Studies, Strategies and Concepts for Women's Health in Women's Hands: A Community Approach for the Control of Cancer Cervix in Karnataka, India

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The Kidwai Memorial Institute of Oncology, Bangalore, India, was created in 1973 to be a referral hospital (for the treatment of cancer patients) within the health infrastructure of the state of Karnataka. The hospital became an autonomous institution within the Department of Health and Family Welfare of the Government of Karnataka in 1980, and has since been recognised as one of the Regional Cancer Centres of India.

As a comprehensive cancer centre, the Kidwai Memorial Institute of Oncology is involved in activities such as promotion of health (cancer) awareness, prevention and early detection of cancer besides of course, investigation, diagnosis, management and pain relief of patients with cancer. The institution has two cancer registries - a hospital based registry and a population based registry for patients from the Bangalore Urban Agglomoration.

The Centre is also involved in the task of generating manpower resources for various facets of the field of oncology and thus has a variety of training programmes for students at the under-graduate, graduate, postgraduate, sub-speciality and doctoral levels.

The Department of Gynaecologic Oncology one of the departments that was created in 1973, has over the last two decades been involved in the management of women with gynaecological cancers.

The present initiative is a product of the collective experience of the staff working in the department.

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Dedicated to

THE MANY WOMEN
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and

HEALTH PERSONNEL OF THE GOVERNMENT HEALTH INFRASTRUCTURE
WHO ARE FIGHTING AGAINST ALL ODDS

and

THOSE WOMEN MEMBERS OF THE PANCHAYATI RAJ SYSTEMS
WHO ARE CONTRIBUTING POSITIVELY
TO THE WELFARE OF THEIR FELLOW SISTERS

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Editorial Note:

* Phases I, II, III and IV (under preparation) are all parts of the operational field research project - Downstaging Carcinoma Cervix in the Indian context undertaken by the Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology, Bangalore

FOREWORD

ndon Johnson's words, "At a desk I sit, I have learned one great truth, the answer to all our ional problems, the answer to all the problems of the world, comes in a sense, as a single rd and that word is education," describe aptly the results of the attempt of the Department Gynaecologic Oncology, to develop a strategy to downstage cancer cervix.

e workshop and this subsequent report of the deliberations, are products of the concerted ort of the staff of the Department of Gynaecologic Oncology, Kidwai Memorial Institute of cology that is an autonomous institution of the Department of Health and Family Welfare, overnment of Karnataka.

e Government of Karnataka is aware that preventive care is the most important cost-effective ethod of tackling the complex problem of cancer cervix. The goal of this workshop was to co- t interested individuals, institutions and organisations to participate in this effort. Our health re system in synthesis with non-governmental agencies along with the women in the Panchayati aj system should be able to create a robust atmosphere to educate and enlighten women on the eventive aspects of cancer cervix i.e. self care with regard to cancer cervix.

is hoped that this report, while seeking to highlight the discussions which were well-seized out the variety, complexity and seriousness of the problem of cancer cervix, may contribute the early implementation of methods for imparting health awareness and early detection of is disease.

angalore.
ecember 1995

Suresh I.A.S
Secretary II
Department of Health and Family Welfare
Government of Karnataka

PREFACE

ndian Obstetrician - Gynaecologists have been involved in opportunistic screening in medical nstitutions that are mainly in urban areas. Attention in rural areas has consisted mainly of Cancer Detection camps, which have been sporadic and unsystematic.

Cytology is the gold standard for cervical screening. Developed countries have been able to control the disease by organised cytology based screening programmes. However financial and other constraints prevent the widespread availability of cytology in India.

The effect of these lacunae in preventive health care is visible through women presenting for treatment with advanced disease, at which stage the results of therapy are far from encouraging, when compared to the effort and time spent by medical personnel besides of course the financial implications of such treatment. When faced with this reality, the staff of the Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology, felt that in addition to patient care and the development of the Subspecialty of Gynaecologic Oncology (which essentially consists of the scientific facets of investigations, diagnosis, therapy both surgery and chemotherapy, followup, palliative care and painrelief of patients), sufficient effort must be made to develop an appropriate strategy for the control of cancer cervix in the Indian situation besides of course collaboration with basic science researchers.

These efforts were initiated by the Department in September 1985 and intra-departmental responsibilities were arranged in a manner such that sufficient time was allotted for this activity. The first two phases of this effort were supported by the Indian Council of Medical Research, New Delhi and the World Health Organisation, Geneva through the Ministry of Health, Government of India and two Non-Governmental Organisations - PRAXIS, Bangalore and ADATS, Bagepalli. The experience of these two phases made us feel that in order to achieve any progress, the problem of prevention and early detection of cancer cervix must be taken out into the community. Thus, as a first step the workshop was conceptualised.

The workshop that was held on 27 - 29 November 1995, at the Institute for Social and Economic Change, Nagarabhavi, Bangalore, and the subsequent follow up work has been supported by the Humanist Institute for Cooperation with Developing Countries (Hivos), The Hague, Netherlands and the MacArthur Foundation, Chicago, United States of America.

The attempt was to bring together representatives of non-governmental organisations, the government and government health infrastructure, social activists, social scientists, academicians and health professionals. At every stage an attempt was made to provide the participants with a frame of reference to understand and assess the issues involved.

The deliberations started with a series of guest lectures by internationally recognised experts which has been summarised in Section I. The observations and data of the two phases of the study undertaken by the Department of Gynaecologic Oncology was discussed along with presentations by representatives from the Government Health infrastructure and PRAXIS and these have been summarised in Section II. This was followed by the presentation of studies undertaken by various community based initiatives, and their relevance to the control of cancer cervix. The sessions of the last day were devoted to future concepts and discussions as to the ways of integrating the three important components i.e. government health infrastructure, non-governmental organisations and panchayati raj institutions, for control of cancer cervix, with KMIO playing the pivotal role. Representatives of the Government of Karnataka made a special effort to be present at first session of the day and interacted positively with the participants. At the concluding session, concrete plans were made for follow up activity involving the NGO's and the Bangalore City Corporation. The highlights of the discussions that took place during the various sessions are given under the heading of "discussion issues" and "discussion outcome".

The proceedings of the workshop have been organised in a manner such that our perceptions of the outcome of the discussions are indicated. No attempt has been made to include "state of the art" information, as our aim has not been to produce an academic treatise on cancer cervix.

Our impression that progress in the practical application of the principles of Preventive Oncology for the control of cancer cervix is entirely dependent on the interest, participation and commitment to a partnership of the community and health professionals (both government and nongovernmental) was confirmed by the experience of workshop

The publication of this report has been unavoidably delayed. However we do hope that this report will emphasise to the reader the urgent need for implementing a community approach for the control of cancer cervix. As this report goes to the printer, the field activities of phase III have been completed. However we have been approached by the Health professionals of the Bangalore City Corporation to train some more of their staff. Though this request has been gratifying and convinces us that our efforts have not been in vain, it also brings home to us the need to persevere with our efforts.

Thus in conclusion though it would be overwhelmingly impractical in the Indian situation to have an organised cytology based screening programme for cancer cervix, which is scientifically superior to visual inspection, we cannot wait indefinitely for cytology to be made available. The introduction of visual inspection should be seen as a financially viable method of inculcating health awareness about cancer cervix and, in the years to come, a harbinger of a cytology screening programme in India.

1998
Bangalore

Elizabeth Vallikad
Department of Gynaecologic Oncology
Kidwai Memorial Institute of Oncology

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We wish to thank all the participants and resource personnel of the workshop "A Community Approach for the Control of Cancer Cervix" for their presence, active participation and interventions. It was their concern and contribution which added value to the discussions and thus made it a meaningful exchange of experiences and ideas resulting in a purposeful workshop.

We owe special thanks to: Dr. Gita Sen, Indian Institute of Management Bangalore, Ms. Reena Fernandes, Shri Rajendran Nathan, Dr. Shobha Raghuram all of Hivos, Bangalore, Dr. Anu Kumar, The MacArthur Foundation, Chicago and Dr. Jan Stjernsward, World Health Organisation, Geneva, for their support and encouragement when we were conceptualising the workshop and for helping to make it "happen". Their emphasis on the need for both the post-workshop follow-up and the publication of the proceedings gave us every encouragement in this facet of "Community Oncology".

We are especially indebted to Dr. P. Blake, Royal Marsden Hospital, London, U.K., Dr. M. Davy, Australia and Dr. M. Hakama, Tampere, Finland for responding to our call requesting their presence and participation in the workshop.

Prof. N. Anantha, Director, extended to us unstinting support in the research efforts, the workshop and the follow-up activities for which we are grateful.

We would like to place on record the spirit of cooperation within the team at the Department of Gynaecologic Oncology that made this workshop possible.

The task of transcribing the audiotapes was accomplished by Ms Barbara Manas, without which it would have been impossible to bring out this report. This report would not have been possible without the efforts of Ms. Kalpana (Field Supervisor, Downstaging Cancer Cervix in the Indian situation, Department of Gynaecologic Oncology, KMIO, Bangalore) and also the valuable suggestions of Dr. Shobha Raghuram (Deputy Director, Hivos India Regional Office, Bangalore).

Perhaps it would not be out of place to record the support which ranged from financial to technical extended to us for the various phases and activities of this study by the: -

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INTRODUCTION

obally cervical cancer is the fifth most common cancer. Worldwide over 460,000 women are gnosed with cervical cancer each year and over 75% of these women live in developing untries. Morbidity and mortality due to cervical cancer has declined considerably in many estern nations, notably the Nordic countries, during the last several decades due to the roduction of organized cytology-based screening programmes. Screening programs in Finnd, for early detection of cervical cancer began in the mid-1960s; the age-adjusted incidence er million) of carcinoma cervix declined from 138 during 1966-70 to 48 during 1981-1985. owever, despite the development of screening technology and treatment methods, no such amatic decline in morbidity and mortality due to cervical cancer has been observed in most arts of Asia, Africa, and Latin America.

ach year approximately 71,600 new cases of cervical cancer occur in India, i.e. nearly 16% f the global total of cases of cervical cancer. The National Cancer Registry Project of the ndian Council of Medical Research has estimated that the annual incidence of gynecological ancers (including cancers of the uterine cervix, body of the uterus, and ovaries, among others) aries between 31.6 and 41.5 per 100,000 women.

rof. Subod Mitra, the Father of Gynaecologic Oncology in India, observed in the Journal of Obstetrics and Gynaecology of India (September 1961), that at the Chittaranjan Cancer Hospital, Calcutta, during the period between 1954 - 1958, cancer cervix comprised of 50.1 % of emale malignancies and 88.2 % of gynaecological malignancies. Prof. Paranjothy, in the same ournal, presented the age and stage distribution of the disease, as observed between 1955 and 960, at the Christian Medical College, Vellore, Fig. 1 (refer page 8). Prof. Naidu in the same ournal observed that only 0.6% of cases presented for treatment at Stage 0 at the Radium nstitute and Cancer Hospital, Hyderabad.

The observations of the Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology were that between 1980 and 1986, cancer cervix formed more than 40 % of female malignancies and 88.47 % of gynaecological malignancies. Out of these, only 0.32% of cases presented for treatment at Stage 0. The age and stage distributions are comparable with the observations of Prof. Paranjothy, Department of Obstetrics and Gynaecology, Christian Medical College, Vellore, Fig. 2 (refer page 8). Thus, it may be observed that the magnitude of the problem has remained at the status quo for more than 30 years. About 84% of these women were between the ages of 35 and 65 years, and in the majority (97.1%), cancer had spread beyond the cervix at the time of diagnosis. Interviews with women whose disease at diagnosis was FIGO Stages IIB – IV, suggested that the two most likely reasons for delay in seeking treatment were: lack of awareness of the symptoms of cervical cancer (57.6%) and inadequate advice by medical personnel to whom they had reported their symptoms (33.7%).

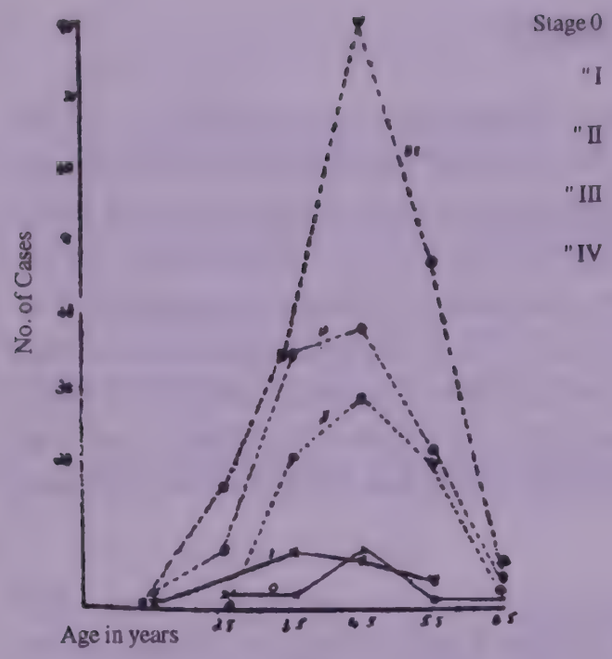

Fig. 1: Age distribution according to stage
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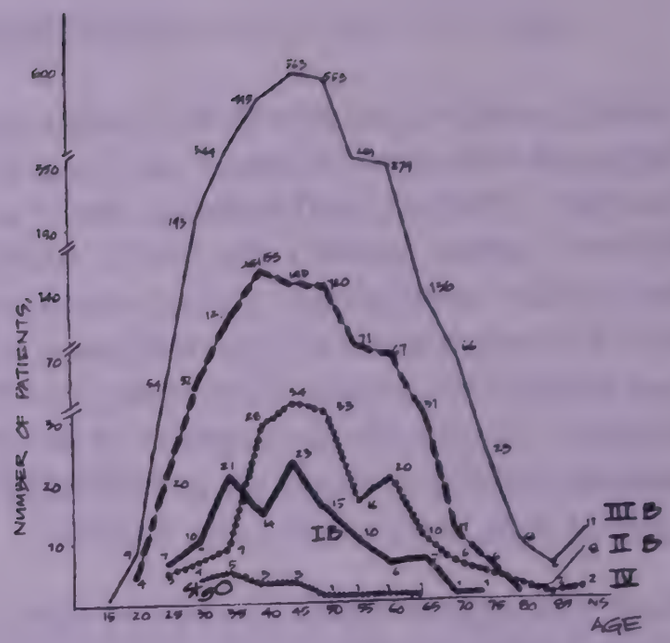

Fig. 2: Age distribution according to stage
Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology, Bangalore 1986

Prognosis after treatment for carcinoma cervix declines considerably as the stage of disease advances. Information on 32,000 patients with cervical cancer treated at 120 cancer centres in primarily developed countries analysed by the International Federation of Gynecology and Obstetrics calculated the following five year survival rates by stage of disease: stage I, 78%; stage II, 57%; stage III, 31%; and stage IV, 8%. Treatment of pre-invasive disease has been observed to result in five-year survival rates as high as 100%. Thus, early detection has the potential to markedly reduce cervical cancer mortality.

The primary goal of public health efforts should be to promote early detection through screening programmes in areas where women are primarily diagnosed with advanced stage cervical cancer (or not diagnosed at all), and morbidity and mortality rates are high due to the disease. The success of screening programs depends in part on the extent of coverage; significant declines in mortality were accomplished in many developed countries only by screening at least 60% of women at risk for disease. Cytology-based screening programmes of this scale are not feasible in many developing countries, especially in India, where it has been estimated by the Indian Council of Medical Research in 1986 that even with a 12-fold increase in cytology services only 25% of women at risk could be covered by the year 2000 AD.

Hence, alternative methods for early detection of carcinoma cervix have been explored. The World Health Organization (WHO) introduced the concept of "downstaging cancer cervix" (detection of early stage disease) by visual inspection in 1986. This strategy involves visual inspection of the cervix using a speculum by nurses and other health workers. This approach could become the key method of early detection of carcinoma cervix in resource-constrained settings.

A. DOWNSTAGING CANCER CERVIX IN THE INDIAN CONTEXT

The Department of Gynaecologic Oncology, KMIO, was supported by the Indian Council of Medical Research (ICMR) in 1991 and subsequently concurrently, by the World Health Organisation (through the Ministry of Health, Government of India) in 1992, to assess the feasibility of using the existing public health infrastructure to downstage cervical cancer. The two reseaarch projects aimed to determine the effectiveness of women health personnel (both health workers and lady medical officers of the existing health infrastructure) in imparting health education on cervical cancer; performing visual inspection of the cervix and triaging its appearance into normal, abnormal and suspicious of malignancy; and making appropriate referrals. These studies were conducted in Bangalore Rural District in communities served by five primary health centres (PHCs). Anganwadi workers were used to impart health education in one of the primary health centres. Intervention studies were carried out in the areas covered by four primary health centres while the fifth served as a control zone. These studies are now considered to be Phase I of the attempt to develop a strategy for downstaging cancer cervix.

The results indicated that although staff of the primary health centres could perform visual inspection of the cervix for early detection of cancer, disseminating information and empowering women with knowledge about cervical cancer could not be their sole responsibility. We had attempted to involve the mahila mandals that already existed in these areas, which however were too few in numbers to have any effect. Thus, the Department of Gynaecologic Oncology, KMIO began to seek alternative avenues to raising awareness and these efforts are considered as Phase II in the attempt to develop a strategy for downstaging cancer cervix.

Several options were considered. First, it was recognized that a number of non-governmental organizations (NGOs) had developed a broad-based, collaborative approach to health, and therefore, had the potential to play an important role in cervical cancer control efforts. An attempt was made to examine the feasibility of this option, by collaborating with two NGOs and the PHCs serving the same communities. These NGOs disseminated information regarding cervical cancer, and encouraged women to demand visual inspection from the trained health workers. It was found that with the involvement of the NGOs, the primary health care staff were able to screen a larger number of women than in the earlier study.

A second potential strategy for control of carcinoma cervix was through the involvement of the women panchayat members (in the study areas) who comprise approximately 30% of the system. Attempts were made to motivate these women panchayat members about early detection of cancer cervix in order to encourage women, particularly those in the high-risk age group (35 - 64 years), to seek screening for cervical cancer.

The workshop entitled "Women's health in Women's hands: A Community Approach for the Control of Cancer Cervix" was therefore organized to further explore these options, and to develop a viable policy for the early detection of cervical cancer.

B. "WOMEN'S HEALTH IN WOMEN'S HANDS: A COMMUNITY APPROACH FOR THE CONTROL OF CANCER CERVIX IN KARNATAKA"

The objectives of the workshop were:

- to create a forum where cancer specialists interact with the Panchayat system; NGO's with an interest in health; members of the health infrastructure; officials of the Departments of Health and Family Welfare, Women and Child Development, and Rural Health and Panchayati Raj; and policy planners, in order to share experiences and examine strategies with a view to develop a plan of action for the control of cancer cervix;

- to propose that the Departments of Health and Family Welfare, Women and Child Development, Rural Development, and Panchayati Raj, and the health infrastructure of the Government of Karnataka, NGOs, and the Department of Gynaecologic Oncology at KMIO work in tandem to undertake early detection of cancer cervix;

- to create an awareness that health workers can be technically equipped to carry out prevention and early detection of cancer cervix;

- to prepare to launch a campaign for early detection of cancer cervix.

SECTION I

CERVICAL CANCER: A BRIEF REVIEW

1. GLOBAL EPIDEMIOLOGY OF CERVICAL CANCER

Globally, cervical cancer is the second most common cancer among women (following breast cancer). However, the geographical distribution of cervical cancer varies considerably and in Asia, cancer cervix is much more common among women than cancers of the breast, mouth and pharynx; thus, cancers associated with tobacco are the third leading cause of cancer morbidity in Asia.

Trends in survival

The International Federation of Gynaecologists and Obstetricians has been collecting data on cervical cancer from around the world in order to monitor changes in incidence and survival as a result of the progress in diagnosis and treatment. They have classified cancer cervix into stages ranging from stage I in which cancer is confined to the cervix to stage IV in which the disease has spread to other parts of the body. Globally, only about one-third of all women diagnosed with cervical cancer have stage I disease. Nearly 80% of these women survive the first five years after treatment. An additional third of women with cervical cancer are diagnosed with stage II disease, and nearly 57% survive the first five years. Five-year survival rates are considerably lower among women diagnosed with stages III and IV disease. The majority of patients in India present for treatment with advanced stage disease. Clearly, if cervical cancer is detected in the earlier stages, considerable suffering can be ameliorated.

Data collected by the International Federation of Obstetricians and Gynaecologists between 1950 and 1978, indicate that five-year survival rates associated with each stage of cervical cancer have been stable. Thus, it appears that there has been little improvement in treatment methods. The most effective approach to decreasing suffering and mortality due to cervical cancer remains early detection; in this context, identifying methods for early diagnosis is critical.

Risk factors

Research suggests that cervical cancer may be sexually transmitted, and has implicated the human papilloma virus (HPV). Women who are sexually active are at higher risk of disease when compared with women who have not been sexually active. Studies in addition, indicate that women who have multiple sexual partners, and women whose partner(s) has/have multiple sexual partners are at higher risk. Studies also indicate that if a man's first wife has developed cancer cervix, subsequent women whom he marries or has sexual relations with, may have an increased risk of cervical cancer. Clearly, cervical cancer prevention efforts need to involve both women and men. The "male risk" needs to be considered in developing a strategy in these efforts. Therefore the use of condoms may be one way of decreasing the risk to the female cervix.

Hygiene practices have also been implicated. Prof. Davy suggested that there might be multiple carcinogens involved in the aetiology of cancer cervix, which may be transmitted during sexual intercourse; hygiene may reduce the probability of transmission. Thus, improving hygiene may be more important than any other factor in controlling this disease.

Studies suggest that smoking may be a risk factor. The risk of developing cervix cancer is about three times higher among women who smoke than among women who do not smoke. The prevention and control of smoking should form an important part of cancer prevention programmes in India.

The role of oral contraceptives in the development of cancer cervix is unclear. Increased risk associated with oral contraceptives may be due to better surveillance of users, to increased sexual freedom, or due to physiological effects.

Prevention and control

The aetiology of cervical cancer is multifactorial. Factors such as infection with HPV, cigarette smoking, hygiene, and diet may be involved. There will be no one approach to the prevention of this disease. Public health efforts will need to involve both men and women, and address a range of issues. The involvement of men in the promotion of sexual health has received inadequate attention. Field experiences indicate that many men are unwilling to be examined for sexually transmitted infections, and to undergo treatment. Public health efforts will have to address this issue.

Health education regarding the role of sexual practices in the etiology of cervical cancer should ideally be a part of a broader public health programme on reproductive health. According to Dr. Stjernsward of the WHO,

> *We cannot teach girls one sexual lifestyle for sexually transmitted disease, one for cervical cancer, and one for AIDS. We must get these programmes together, and there we have to start with persons of school-age, above 11 years. [Furthermore,] it should be a positive health promotion message.*

It is particularly important that cervical cancer control initiatives do not become obsessed with the issue of number of sexual partners or "promiscuity." Advocating celibacy or monogamy is unlikely to be successful. Moreover, assessing "promiscuity" is not as straightforward as counting the number of partners; it is often a value judgment. Public health programmes in Australia do not talk about counting, but instead take the position that any woman who has ever had sexual intercourse is at risk of developing cervical cancer. Thus, all women who have ever had sexual intercourse are encouraged to be screened for the disease.

One potential screening approach in India is the use of cytology, the use of which is internationally established. Cytology attempts to identify pre-cancerous lesions, i.e. changes in the cervix before they become cancer, and thus, forms one method of primary prevention. The public

health approach in the West is based on cytology. All women are recommended to have a smear test, and if the smear test is abnormal, then they undergo further tests such as Colposcopy to confirm the presence of pre-cancerous changes. When such changes are found, the usual method of treatment is removal of these cells, and the prevention of their progression to a malignancy.

The impact of the cytology approach on the incidence of and mortality due to cervical cancer is apparent in the Nordic countries. Iceland and Finland began routine mass screening for cervical cancer in the 1960s. The aim was to provide cytological screening to all women above 30 years. The incidence decreased considerably in these countries subsequently, to as low as five per hundred thousand women in Finland by the mid 1980s. When compared to Finland and Iceland, Norway had opportunistic screening, that is, only women who requested a smear test from their physician were screened. The incidence of cancer cervix did not decrease as dramatically in Norway. Thus, the lesson from the Scandinavian experience is that screening programmes will be effective only if all women at risk are included.

Prospects for a vaccine against cervical cancer

As observed earlier, a number of studies have indicated the involvement of the human papilloma virus, particularly HPV 16 and 18. The incidence of cervical cancer is low in countries such as Spain and Israel, and the prevalence of infection with HPV 16 or 18 is also low whereas in areas with a high incidence of cervical cancer such as Colombia, the prevalence of HPV infection is also relatively high. An anti-HPV vaccine may be ready for Phase I trials some time during the next decade. Dr. Stjernsward has predicted that a vaccine is likely to be available before a meaningful, high quality cytology screening programme is introduced in India.

2. CYTOLOGY-BASED SCREENING: CRITERIA AND IMPLICATIONS

The primary approach to the prevention and control of cervical cancer in the West has been cytology-based screening. The aims of a screening programme include detection of pre-invasive cancer; prevention of death from cancer; and improvement of quality of life.

Screening programmes, which do not demonstrate the achievement of the above aims are useless.

The International Union for Cancer Control (UICC) concluded several years ago that screening for cervical cancer is effective, and can be promoted as sound public health policy. However, there are several issues that need to be considered when implementing cervical cancer screening programmes. These include whether screening should be:

* organised or opportunistic
* selective or general
* single or multiple phase

The Finnish experience indicates that some kind of organisation is necessary for a successful screening programme both in terms of reduction of incidence and mortality and in terms of cost.

An organised approach to providing screening services, making treatment available, and monitoring outcomes is essential, and will have to be developed if screening for cervical cancer is launched in India. The cytology-based screening approach has been successful in Nordic countries such as Finland. The incidence rate of cervical cancer in Finland is one of the lowest in the world. Screening has also had a major impact on the stage distribution of incident cases of cervical cancer; within a few years of the initiation of screening programmes, stage I tumours predominated.

Whether to select specific groups of women for screening or to have a general population-based programme is a complex issue. According to Dr. Hakama, screening recommendations should be made for all women above a certain age, and should specify the frequency of screening. Screening based on risk factors such as sexual activity and number of sexual partners is unlikely to be successful.

The third issue concerns the number of diseases that are screened for at the same time. In general, screening for single diseases have been more effective than that for multiple diseases. This is in part due to differences between diseases such as in the age groups affected, and the frequency of screening required.

The data on the optimal interval between screening tests for cervical cancer is available from an International Agency for Research on Cancer coordinated study. The impact of screening was assessed in terms of the estimated reduction in the cumulative incidence of cervical cancer among women between the ages of 35 and 64 years. The incidence will decrease by 93% if the screening is annual. The protective effect of screening depends on the sensitivity of the screening test. The Pap smear test is known to have high sensitivity; other tests need to be evaluated.

Data indicate that starting screening at young ages is not optimal, as the risk of invasive cancer is low, at least in European populations. Screening in Finland began with women aged 40 years and above; later, it was extended to women between 30 and 40 years. The cost of screening women above 35 years in India, will be half of that of screening women above 20 years, and will still identify the majority of cases of cervical cancer.

The feasibility of a cytology-based approach in India should be examined in the context of the epidemiological situation in India. Cancer registries in India have recorded cervical cancer incidence rates as high as 43.5 per hundred thousand in Chennai and as low as 19.4 per hundred thousand in Mumbai. The rural cancer registry in Barshi, Maharashtra has reported an incidence of 29.2 per hundred thousand. Cancer of the cervix is thus the most common cancer among women in India.

Compared with many developed countries, a higher proportion of women in India seek treatment for advanced stage disease. Fewer than 4 per cent of patients present at stage I in India compared to 48 per cent in the United States. Nearly 75 per cent of patients in India present in stages III and IV. While the five-year survival rate is over 80 per cent after treatment for stage

I disease, it is less than 40 per cent for stage II. Thus, proportion of women cured of cervical cancer is extremely low in India.

The Indian National Cancer Registry programme has predicted that by the year 2000 there will be at least 100,000 new cases of invasive cervical cancer in this country. Estimations indicate that if a single smear test is conducted at the age of 40 years, 100 million women will have to be screened, and approximately 20 per cent of cases can be prevented. Thus in this scenario, for each case of cervical cancer prevented, there will be five million smear tests and 250 detected cases.

Therefore, the economic resources required to conduct nation-wide screening programmes prohibit the application of this approach in developing countries. Thus, feasible, innovative solutions are urgently required in such resource-constrained settings.

3. THE AUSTRALIAN EXPERIENCE IN THE CONTROL OF CANCER CERVIX

Background

The best way to deal with a disease that we cannot prevent, is early detection. John Clarke considered as one of the fathers of modern radical surgery for gynaecological malignancy, wrote in 1900, "The earlier the diagnosis, the more certain the prognosis for cure with an operation. The more completely the local process is excised, the more certain the radical cure." Advances in early detection of cervical cancer have done more to control this disease than any advances in treatment. Thus, a key public health approach to cervical cancer is downstaging.

Cancer cervix ranks sixth among the cancers in Australia where approximately 1,000 new cases of cancer cervix are diagnosed annually. Nearly two-thirds of these cases are cured; an aim of cervical cancer prevention and control efforts in India should be to move towards a similar cure rate.

The Australian national screening programme for cervical cancer has been functioning for only about the last three years. Efforts to control cervical cancer were underway in the state of South Australia prior to the launching of the national programme. South Australia has a population of about 1.5 million. It includes an industrial area called the Iron Triangle, which has a large immigrant population. This group which has relatively low education levels has an incidence of cervical cancer which is 50% above the overall incidence of the State. Women with cervical cancer in this population in addition, had twice the death rate of women with cancer cervix in the rest of the State. This was found to be a result of the higher proportion of women in the former group being diagnosed with disease greater than Stage I (nearly 75% versus only approximately 50% in the latter group). As a result of these observations, efforts were launched to identify low-cost, but effective methods of screening for early detection of cervical cancer.

Campaign to control cervical cancer

This programme included a range of activities. First, it involved health education aimed at the general public and health professionals through mass media, women's groups and postal letters. Second, since primarily male physicians who were often of different ethnic origin served the population, the programme promoted health service provision by nurses (predominantly women). Nurses were available to conduct screening tests in the evenings after usual working hours; this helped make the screening test less threatening for women. Third, women were reminded of when they were due for their next smear test.

All those involved in the project (except Prof. Davy) were residents of this area. The project was run by a steering committee, which included nurses, one physician, representatives of women's organizations and other interested groups. Each month the committee was appraised of the number of women who had sought a smear test, the results of the smear tests, and the area of residence of these women. This information helped the local steering committee identify groups who continued to be under-served, and take appropriate action.

Surveys were undertaken to assess the public's knowledge about the project, and about cervical cancer. Women who had a smear test were asked why they were motivated to do so, and women who had not had a test were asked why they did not. The accessibility and acceptability of services was also assessed.

Surveys indicated that many women knew about the smear test, what it was for and why it was recommended. However, many women depended on their physician to advise them about undergoing a screening test. Physicians, predominantly male, were regarded as authoritative figures. Women responded, "It's not up to me to do it, the doctor will tell me when it's important." Other reasons for not having a smear test included embarrassment, fear of diagnosis, or not "getting around to it." It was also observed that older women, who were difficult to reach prior to the health education campaign, were becoming increasingly involved in screening programmes through groups; taking the screening test was added to their group activities. Also, family members, particularly daughters, reminded many older women of their next smear test. Although this may not necessarily work in the Indian setting, it is an example of the resolution of a situation in which women were difficult to reach.

The project was conducted during a two-year period. At the start of the project only about 29% of women in the Iron Triangle had a smear test; by the end of the project, this proportion had doubled. The number of incident cases of cervical cancer was almost halved during this period, and most importantly, a larger proportion of these cases were of stage I disease as opposed to stage III.

The Australian project demonstrates the effectiveness of increasing women's awareness of cervical cancer, its prevention, control and in reducing the morbidity and mortality.

4. STRATEGIES FOR CONTROL OF CANCER CERVIX IN DEVELOPING COUNTRIES: WHO PERSPECTIVE

Data on cervical cancer incidence indicate that nearly five out of every six women with cervical cancer live in developing countries. Risk factors for cervical cancer include being born in a developing country, having few socio-economic resources, lack of access to clean water, and lack of information. Lack of information in women and men, about symptoms, and about the fact that this cancer, if diagnosed early, can be cured, is in part responsible for the greater proportion of advanced stage disease in the developing world. Moreover, even when symptoms are recognised as serious, medical care may not be sought due to lack of family support, particularly that of male partners. Thus, for primary prevention of cervical cancer, it is most important to empower women with information regarding its actiology, early detection, and treatment. However, the involvement of men will be equally critical.

Early detection in addition to primary prevention, is an essential part of the control of cervical cancer. Cure rates for early stage disease are markedly higher than for advanced stage disease. One can enormously increase the proportion of women cured, by downstaging within the existing infrastructure, and without significant additional expenditure. Treating cases without any attempt at early diagnosis is like "hammering on closed doors."

> *India in no way, with 5 % of the resources for controlling cancer, compared to 95 % in developed countries, can go and ape after what is going on there.*

The ICMR study has shown that screening by visual inspection of the cervix can detect early stage disease; about 50% of cases will have early stage cancer in comparison with the current 5%. Cytology-based screening in India is not feasible due to the scale on which it is required (and the concomitant level of resources), and the lack of quality control. Screening if introduced, (by visual inspection), should not cover women below the age of 35 years as this can result in the 'dysplasia swamp'. This is because a number of women may have cervical dysplasia, but a very small proportion of them will in fact go on to develop a malignancy. Thus, for a cost-effective screening programme, screening should have a high coverage of women above 35 years, and should have a low frequency.

Prior to the launching of public health efforts to prevent and downstage cervical cancer, it is critical to ensure the availability and accessibility of therapeutic services. Early detection, treatment, referral networks, and palliative care must be linked in a formal system. The males may need a different approach. It's no use empowering women, if diagnosis, referral and treatment are not guaranteed.

> *Don't underestimate the Indian rural women. If you send home cured patients you get compliance. Otherwise she goes home when she realises that it is meaningless to hang about as she sees the result of therapy.*

Curative treatment is not the last step in the process. When therapy cannot be given or when it fails, palliative care should be provided. Nearly 80-90 per cent of pain can be managed using drugs, which cost less than aspirin. A great deal of unacceptable, unnecessary suffering can be avoided. An innovative programme in Calicut has involved families and health worker volunteers in cancer prevention. Clearly, in addition to the empowerment of women and their families, the provision of training to health care workers and the necessary infrastructure with which to implement this training will be crucial for the success of public health efforts.

The WHO, in collaboration with national and local governments, non-governmental organisations, cancer institutes such as KMIO, and the World Bank, hopes to revolutionise cancer control using the above approach in prevention and early detection. This concept is built on the WHO's simple principle that nothing can have a bigger impact than implementing the enormous knowledge already available. This approach, if successful, should result in a downward shift in the distribution of disease stages at diagnosis.

5. CONTROL OF CANCER CERVIX: PERSPECTIVE OF THE NATIONAL CANCER CONTROL PROGRAMME, INDIA

Data from Regional Cancer Centres indicate that there are regional differences in the incidence of cervical cancer in India. The incidence in Mumbai, is less than 20 per 100,000 while in Bangalore it is 26 per 100,000. It is highest in Chennai. Data from the greater Mumbai metropolitan area show that over the last few years, unlike other parts of the country, the incidence of breast cancer is greater than that of cancer cervix. Difference in "lifestyles" may be a reason for breast cancer being the leading cancer among women in the greater Mumbai area.

An analysis of secular trends in cancer cervix in India over a number of decades by Nothani, reveals that there was a definite decline in the incidence of cancer cervix in the 1960s and the 1970s, and contrary to popular notions, it has been stable since the 1980s. The decline may in part be due to an increase in the mean age at marriage. The reasons for the plateauing of the incidence rate are unclear.

There will be, if current incidence rates hold, nearly 250,000 prevalent cases of cancer cervix in India by the turn of the century. Prevalent cases include those who have been diagnosed with the disease and still alive, and new cases being diagnosed in a given time period. This is an issue, which cannot be ignored.

Approximately 20,000 women with cervical cancer sought care between 1981 and 1992, at the Tata Memorial Hospital in Mumbai. More than 62% were diagnosed with advanced stage disease. There is very little that can be done for these women in terms of therapy. It is a pity because cervical cancer is one of the easiest cancers to detect and diagnose. Women experience bleeding and foul-smelling discharges; the process does not take place overnight. Thus, if

women have the opportunity to become aware of symptoms, and if aware of the significance of their symptoms, they will seek the opportunity to avail medical care.

Treatment of late stage disease is less effective (in terms of five year survival and cure) than treatment at early stages. Early stage disease can be successfully treated by either surgery or radiation therapy, but in the advanced stages, only radiation therapy and palliation are useful. Essentially, women are treated with external radiation to the pelvis, i.e to the primary tumour and the drainage lymph nodes; the treatment lasts for a period of anywhere from four to six weeks. Women, who do not live in one of the metropolitan cities where cancer treatment is available, have to travel long distances at great cost. Cervical cancer becomes not just a medical problem, but a socio-economic problem, one which entails considerable economic and emotional suffering.

It is in this context that the National Cancer Control Programme (NCCP) in India was conceived. The overall aims for cancer control in India are:

- to promote primary prevention of tobacco related cancers;
- to promote the early diagnosis and treatment of cancer;
- to strengthen of therapeutic facilities and ensuring availability of pain relief measures;
- to augment and develop regional cancer centres around the country;
- to augment facilities in medical colleges;
- to develop cancer therapy facilities at smaller district hospitals in order to provide services to individuals in whom cancers are detected at an early stage;
- to establish population- and hospital-based registries;
- to develop human resources;
- to create public awareness about cancer.

Currently, there are few resources for cancer control. Eleven regional cancer centres and 24 cancer detection centres have been established in the country. Fewer than 2500 beds have been earmarked as cancer beds in the government medical care system. There are approximately 207 radiotherapy units; at least 800 units are required. However, this scenario is changing. Regional hospitals with radiotherapy units are being set up. The private sector, notably in South India, is increasingly providing cancer detection and treatment facilities; however, these services are likely to be accessible to only a minority of the population.

Resources to downstage cervical cancer need to be developed. The experience of the NCCP in Barshi, Maharashtra indicates that by providing information about and services for the treat-

ment of cervical cancer, the proportion of women diagnosed with early stage disease can be increased considerably in a relatively short period of time. The proportion of women diagnosed with earlier stage cervical cancer in Barshi, increased from approximately 35% to 48% between 1988 and 1992.

The costs and benefits of downstaging cervical cancer

Dr. Dinshaw indicated that treatment of early stage cancer is not less expensive (or less technology intensive) than late stage disease; however, she stressed the fact that treatment of early stage disease is more effective because of higher rates of survival and cure.

According to Dr. Stjernsward, the three most cost effective cancer prevention and control activities are the prevention of tobacco use, the control of cervical cancer, and palliative care (by which quality of life can be improved with very little monetary input). He cited the Sri Lankan approach to the control of oral cancer (which can be treated effectively in the early stages) as a model for cervical cancer. The models developed by the World Bank for oral cancer suggest that many lives that could be saved by early detection and prevention of oral cancer would be achieved instead of investing primarily in therapeutics (as is occurring in the private sector). A similar conclusion can most likely be made about cervical cancer.

6 DISCUSSION

6.1 Discussion issues

Q (Dr. Halagi): Should screening for cervical cancer be started at the age of 35 years or should it be related to the cultural factors and the younger marriages ?

A (Dr. Vallikad): The majority of women present for treatment between the ages of 35 and 64 years and if the screening test is visual inspection then it is best to have women aged between 35 and 64 years as the target group. Moreover we do not have the resources to extend such a programme for a larger age group. Starting at an earlier age would mean entering the "dysplasia swamp" as described by Dr. Stjernsward. This would also happen if such a preventive programme is linked with the family planning programme, where the age group would be much lower.

Q (Dr. Sen): Are we then in India really talking about male sexual behaviour and are there community studies that tell us about what is going on with that in terms of the papilloma virus and its spread ?

A (Dr. Vallikad): We have done a study at KMIO in which men, unlike women, did report multiple sexual partners.

A (Dr. Hakama): Cervical cancer does not develop because of only one risk factor but there is multistep carcinoma genesis. This aspect has to be handled with care and we should have a cancer control programme that does not make men and women feel guilty.

A (Dr. Davy): It is very important that we do not get hung up on "how many partners have you had?" What is promiscuity? Very often the definition is considered to be " In my opinion promiscuity is any one who has had more partners than I have had?" Thus we need to remove the stigma and bring it back to the grassroots so that all women who ever had sexual intercourse are screened for the disease. This will encourage all women to come for the test – whatever may be the test. There are theories that the papilloma virus may be implicated but there are also cofactors. We do not know whether all cervices are susceptible all of the time or only part of the time or only some are susceptible. We also do not know whether all males carry the transmittable factor at some stage or only part of the time. Thus there are many unknowns – all we can say at this stage is that there are multiple carcinogens, which are sexually transmitted, and that hygiene may reduce this process.

6.2 Discussion outcome:

The discussions on the risk factors for cervical cancer and implications for public health concluded that cancer control efforts should:

- not focus solely on "promiscuity"
- involve both men and women (in activities such as health education, treatment of STDs)
- promote early detection through appropriate screening methods for appropriate age groups, without linking with another unrelated programme.
- facilitate safe hygiene practice.

SECTION II

A COMMUNITY APPROACH FOR DOWNSTAGING CARCINOMA CERVIX

7. DOWNSTAGING CARCINOMA CERVIX IN THE INDIAN CONTEXT - PHASE I: THE ROLE OF THE GOVERNMENT INFRASTRUCTURE

7.1 Description of the study

7.1.1 Background

Cervical cancer is the most common gynaecological cancer seen at KMIO. The majority of women diagnosed with this disease are between 35 and 64 years. They are mainly from rural areas, and are of low socio-economic status. The majority present with advanced disease.

Ninety two percent of women diagnosed with cervical cancer present with disease that has spread beyond the cervix; 41% of women do not begin treatment. According to Dr. Vallikad, at KMIO:

> *Some women with cervical cancer walk in; get their biopsies done; give their blood for testing; walk out; we never see them again.*
>
> *More than 50% of women who start treatment do not complete it. About 66% of women who seek treatment for advanced stage disease are unaware of the significance of the symptoms of the disease; 26 per cent of them reported having gone to physicians, and being given B-Complex injections, and/or tonics. They were referred to Kidwai only when symptoms and mal-odour became acute and obvious.*

These data were reviewed in 1986, and it became evident that making information about cervical cancer available to women, and detecting cervical cancer early was of high priority. Subsequently, the WHO introduced the concept of visual inspection (VI) of the cervix.

Arguments against the use of visual inspection were that it is less sensitive, needs to be done frequently and that it depends on an already overworked group of health workers. Arguments in favour of downstaging cervical cancer through visual inspection were that it could decrease mortality, requires very little additional investment and would precede introduction of cytology whenever feasible. Hence, in a resource-limited setting in which further investments are unlikely, visual inspection may prove to be the only immediate short-term solution.

7.1.2 Study hypothesis

The study was initiated in 1991 to examine the feasibility of such an approach. The hypothesis was that raising women's awareness about cervical cancer and training women primary health care personnel (nurse midwives and physicians) in visual inspection would result in a significant downstaging of cervical cancer. *No incentive was given to health care personnel who*

participated in the study in order to test an approach that could be replicated on a large scale within the existing health infrastructure.

7.1.3 Methods

The study was designed as a community-based intervention trial and involved villages covered by five primary health centres (PHCs) in Bangalore Rural District, Karnataka. Interventions (health education regarding cervical cancer and provision of visual inspection services in all and in addition cytology in two) were introduced in four PHCs while the fifth served as a control. Differences in women's level of awareness of cervical cancer and in the stage distribution of diagnosed cases between the intervention and control zones were the hypothesised outcomes of the intervention. The aim was to develop and test a strategy that was simple and replicable so the health infrastructure could implement it without the help of KMIO. Thus it would be included as part of the regular work of the health infrastructure.

Table 1 indicates the interventions that took place in four of the five areas included in the study:

Table 1. Project activities and involved health personnel

		Area 1	Area 2	Area 3	Area 4
Activities in the Field	Health Education	Female Junior Health Visitors* (JHV); Male JHV; Block Health Educators	Female JHV; Male JHV; Block Health Educators	Female JHV; Male JHV; Block Health Educators	Anganwadi Worker; Male JHV; Block Health Educators
	Visual Inspection	Female JHV	—	Female JHV	—
	Cervical Cytology	Female JHV	—	—	—
Activities at the PHC	Visual Inspection	Lady Medical Officer (LMO)	LMO	LMO	LMO
	Cervical Cytology	LMO	LMO	—	—

* Previously known as Auxiliary Nurse Midwives

No intervention was introduced in the fifth area (the control zone). *All health personnel who were responsible for doing visual inspection (VI) underwent a two-day training session at KMIO.* They were taught to note the appearance of the cervix (its colour, shape, size, surface, the presence of any discharge or bleeding), and based on the observation to decide whether the cervix was normal, abnormal or suspicious of malignancy. *All health personnel involved in*

imparting health education underwent a one-day health education training session at KMIO. They were provided with a torch, sufficient specula, gloves, and appropriate stationary for record keeping. Those performing cytology were provided with slides, a slide box, a glass marking pencil and fixative solution. They were taught about the necessary procedure that had to be followed to sterilise the gloves and the specula. The JHV could perform the tests at the PHC, Primary Health Unit, and the village school or at the homes of the women, according to their convenience and that of the concerned women – thus there were no fixed guidelines for the place or time of the test. Though it was suggested that they examine at least five women in a day, no target numbers were set for the JHV or the LMO.

The referral process and treatment guidelines used in the field are given in Table 2.

Table 2. Referral process

	Area 1	Area 2	Area 3	Area 4
Female JHV	VI* result: referral to PHC if cervical abnormalities seen or suspicious of malignancy	—	VI result: referral to PHC if cervical abnormalities seen or suspicious of malignancy	—
LMO	Repeat VI and cervical cytology	Conduct VI and cervical cytology	Repeat VI and refer to KMIO if suspicious of malignancy	Conduct VI and refer to KMIO if suspicious of malignancy
	Cytology test result:	Cytology test result:		
	Class I: no action	Class I: no action		
	Class II: antibiotics prescribed; repeat smear.	Class II: antibiotics prescribed; repeat smear.		
	Class III or higher: refer to KMIO	Class III or higher: refer to KMIO		

* Visual Inspection

All women who reached KMIO as a result of referral from the PHC underwent visual inspection. Women would register with the Hospital Cancer Registry, if a lesion was visible, and receive appropriate treatment. Women would register in the Department's dysplasia clinic, if no lesion was visible, and undergo further investigations (such as Pap smear, colposcopy, etc.).

The Department of Gynaecologic Oncology had no active role in the field intervention beyond the initial training input, that is, the Department did not do health education or examinations of

the women in the field. However, monitoring the progress of the intervention was undertaken in two ways. The first was through copies of records maintained by the JHVs, LMOs and Anganwadi workers about the women to whom they had imparted health education and/or examined, which were submitted to Department personnel at the monthly PHC meetings. The number of women who were referred to the Department for re-examination and additional testing, and the outcome of referrals were also recorded. Secondly, independent assessments of the field activities were undertaken by the project staff by re-examination of a sample of women who had been examined, and by tracking down those who were non adherent to the advice that they had been given by the health personnel.

The original outcomes of interest included differences in the level of women's awareness of cervical cancer and in the stage distribution of diagnosed cases. A "Knowledge, Attitude, Practice" (KAP) survey was conducted among a representative sample of women between 30 and 60 years in all five areas at baseline in order to measure changes in levels of awareness. The survey was repeated in the same sample at the end of two years of intervention. The stage distribution of cases diagnosed in the intervention areas was recorded based on the cases who were referred to KMIO by local health personnel; the stage distribution of cases diagnosed in the control zone was recorded based on cases identified through the hospital, population-based cancer registries and information received from other institutions.

7.1.4 Results

The overall coverage of the interventions was low (see Table 3). The highest proportion of women in the age group of interest reached by health education efforts was in Area 2 (18.5%) where JHVs were responsible only for communicating information on cervical cancer. Moreover, as the number of women reached by the intervention process was low, no significance could be attributed to the second KAP survey that was undertaken.

Table 3. Number of women age 35-60 years reached by interventions

	PHC I	PHC II	PHC III	PHC IV
Women reached with health education	344	936	824	131
Women screened by VI in the field*	338 (6)	-NA-	530 (294)	-NA-
Women referred to PHC for screening who in fact were screened**	-NA-	243	-NA-	36

* Number in parentheses refers to number of women who refused to be screened by VI

** In PHC II and PHC IV screening was only conducted at the PHC; field health workers would refer all women in the age group of interest to whom they gave information on cervical cancer to the PHC for screening.

Note: The approximate size of the population of interest (women between 35 and 60 years) is 5000 in each area.

Attempts were made to re-examine a 10% random sample of women who were classified as having a normal cervix and all women who were classified as having a cervix which was abnormal or suspicious of malignancy in order to examine the accuracy of health workers' visual inspection diagnoses. Concordance between the two ranged widely, but since a very small proportion of these women were in fact re-examined, it is difficult to interpret these figures.

7.2 Perspectives

7.2.1 Women's perspectives

KMIO project staff realized during the project that a number of women were refusing to undergo a visual inspection examination. Project staff interviewed those who refused in order to ascertain reasons for refusal. Women raised the following issues:

- Inadequate advice from health workers: Although the health worker was supposed to have provided information regarding the need for visual inspection, what it entails etc., women were not aware of the need to undergo the early detection test. They did not realise that the test may be important even when there were no symptoms.

- Low priority: Taking preventive health measures appeared to be of low priority; many women were concerned with issues of survival (for example, providing the next meal for their family). Many women would utilise health care facilities for their children and other family members more readily than for themselves.

- Lack of economic resources: The early detection of disease and subsequent treatment may impose a considerable economic burden on women, one, which they can ill afford. According to Ms. Kalpana, Field Supervisor, KMIO project:

  There were many women who were not in a position to buy medicines. They would always complain to us saying that, "You only do the check up; then you go away. You never give us medicines, and we cannot buy them."

- Need for consent: Many women have to seek the permission of the head of the household who is usually male to get a health check up. Occasionally, other members of the household such as the mother-in-law or other elder members would have to consent.

- Shyness: A number of women reported being shy about having a gynaecological examination. Some noted that they would not seek gynaecological care at PHC where there was no female physician.

- Fear: A few women refused to be screened because they feared that others in the village would think that they had cancer.

- Limited accessibility to health care: Women have to travel long distances (up to 15 km) to reach a PHC. Often there are no buses that link interior villages to a PHC. Thus, women

end up waiting for the health worker's next visit; however, the health worker may be more concerned with providing family planning services (identifying FP "cases") than with addressing chronic reproductive morbidity such as white discharge or other aspects of women's health such as anaemia or general weakness. Those women who do seek care at a PHC may find that the female physician is unavailable. Such experiences are likely to discourage women from seeking medical care at government facilities.

- Unavailability of physicians at PHC: Physician services may be unavailable at the PHC due to several reasons. First, physicians are transferred frequently, and vacancies may not be filled promptly. PHC physicians have been known to refuse VI on the grounds of being too busy in the KMIO study areas. Others have demanded payment for this service despite KMIO's assurances to women that this would be done free of charge.

- Poor quality service at PHC: Women felt that the government health system lacked a holistic approach to women's health; the system did not address important problems such white discharge and backache. Many physicians would prescribe drugs without a medical examination. Thus, many women reported that they preferred going to a private practitioner.

- Inappropriate advice from health workers: Many health workers advised women to go directly to Kidwai for care. Many women could not afford the travel expenses. There were many JHVs who said, "Don't go to the PHC, go to Kidwai directly".

7.2.2 Perspectives of KMIO project staff

The KMIO project staff encountered several problematic issues during the implementation of the project.

- It was found that the success of the intervention depended to a great extent on the situation at the PHC. The activities proceeded smoothly if an interested woman medical officer was present at the PHC. However, the system would fall apart when she was transferred. The project staff would attempt to interest the new medical officer in the project and maintain the enthusiasm of field workers, but were not often successful.

- It was clear that PHC staff could provide the necessary medical services; however, building health awareness was a burden for them. Screening tests should be available at the PHC and health workers such as the JHV should be skilled in performing them. The process of creating demand for these services, and ensuring their utilization should not be the health workers' responsibility. Dr. Vallikad noted:

  And right now, I think what happens is that you are burdening them with the task of doing health education. As a result of that, the delivery of health services gets affected, because they have to do both health education and deliver the goods. It's too much.

- The study, as it was conceived and conducted, focused on women in the community and women health workers. A knowledge, attitudes and practices (KAP) survey was conducted during the preparatory phase of the study. Many women reported that they needed the consent of their husband or mother-in-law to have a health test. Thus, it was realized that both the empowerment of women and the education of men were required.

- Project staff held educational sessions for male health workers and block health educators. The aim of these sessions was to make them aware of a screening test for early detection of cervical cancer, and to enlist their support in reaching this information to the community.

  Future initiatives will need to address the issue of women's empowerment and men's involvement more extensively.

7.2.3 Perspectives of members of the government health infrastructure

The following are the observations of the Government Health Infrastructure who participated in the workshop:

- Difficult working conditions for health workers: Local health workers are overburdened with work. This became evident when project staff discussed women's inability to consult PHC personnel with local health workers. The latter have to maintain 16 registers, and meet targets set by various target-achieving programmes. Imparting health education is time consuming. Moreover, it must be scheduled according to women's time availability.

- Women consented to have a visual inspection test in their home in several instances. However, when they realised that instruments had to be sterilized in their home, and that they would have to provide a stove and bowl for sterilization, they refused.

- Many women work outside the home (in agriculture, in factories). Thus, many are not at home when the health worker visits the village.

- Health workers also reported that they were not given any financial reward for their work.

7.3 Discussion

7.3.1 Discussion issues

(a) General

Representatives of the government health infrastructure in the various taluks that participated in the KMIO project to downstage carcinoma cervix also presented their experiences. Dr. Srinivasa Gowda described the training and field activities of the government health personnel involved in the KMIO initiative. Several others spoke of the practical difficulties faced in implementing the project. Ms. T. Nirmala, a junior health visitor in Anekal Taluk, noted that

JHVS (who were charged with doing cervical cancer screening) were overburdened; their existing responsibilities include registration of births and deaths, ante-natal care, and family planning. Moreover, they are expected to carry out these functions with extremely limited resources. For example, they often have no means of transportation, and end up having to walk long distances. The JHVs found that they could not always sterilize speculums between examinations because many households they visited lacked stoves and fuel and hence could not examine all the women that they actually could have.

Women's reluctance to undergo cervical cancer screening by visual inspection of the cervix was also raised. Ms. Nirmala observed that older women were often fatalistic:

> *If they are aged, they don't care. They say, "I am going to die, so what's the use of trying to do any investigation for me?"*

According to Ms. Anthony Mary, an Anganwadi supervisor in Jigani Circle, lack of accessibility of the PHC and the absence of doctors in the PHC often discouraged women from coming forward for screening or follow-up (when screening was done in the field). Dr. Rukmini Ramachandra, Bidadi PHC, noted that even when women consented to a gynecological examination and a problem was identified, factors such as poverty and lack of support from family members often prevented women from taking action. Ms. Uma, an Anganwadi worker in Jigani Circle, also emphasised these factors. Women who are daily wage earners do not have the time or money to go to the PHC, particularly in the absence of obvious disease symptoms.

> *Sometimes women say, "You give me money, you pay the charges, then I will come [to the PHC]."*

Ms. Srilata Batliwala further highlighted the importance of examining the socioeconomic and psychological dimensions of seeking health care. Surveys of rural indebtedness have revealed that medical care is the second most common cause of debt among rural households.

> *For the poor, any kind of check up, any kind of visit to a health centre spells expenditure, and debt. So I think this is one thing that is always operating in the background.*

Furthermore, women's "feelings about everything below the waist" pose another barrier to seeking health care

> *The whole part of the body below the waist in our culture is treated as a source of shame; it's something to be hidden; it's something that you don't talk about.*

Programmes which seek to promote women's health must address this issue; health education cannot simply provide facts about illnesses and how they arise, but must also attempt to change perceptions of the body, particularly the "body below the waist".

(b) The role of village health workers in cancer control

Q: (Mr. Ramalinge Gowda): Village health workers such as the anganwadi worker were chosen to participate in the KMIO cancer project. Health workers, in addition to the long list of activities that they are officially responsible for, are often incorporated into various additional programmes such as the one under discussion here. As a result, they are unsure of the demarcation of their duties. How do you foresee the success of this approach?

A: (Dr. Vallikad): The ground reality of the government health infrastructure, its constraints and limitations, are familiar to many individuals involved in health issues in India. The purpose of this workshop is to ascertain how we can go forward in the context of this reality. The results of the KMIO study are before us and its implications are not altogether clear. As we understand it, we feel that the junior health visitor can be trained to do the test. We feel that the anganwadi worker can be used to give health education to population with which she is involved. The lady medical officer can be trained to deliver screening, treatment and referral services at the PHC. The key question facing us is this: How do we enable women to demand and use these services? Formulating answers to this question is the purpose of this workshop.

A: (Dr. Dara Amar): One way of directly reaching local women (other than through village health workers) may be via the use of techniques like Participatory Rural Appraisal (PRA), in which women can be approached directly. Women's groups can be formed. They can be motivated around issues such as the prevention and control of cervical cancer. Moreover, they can function as local monitoring groups who ensure that the government health infrastructure is accountable to women.

(c) The impact of health education on women's demand for health services

Q: The impact of health education efforts appeared to vary by PHC area, and may not be entirely due to differences in the effectiveness of PHC staff. What other factors may have influenced these outcomes?

A: (Dr CM Francis): Several other factors may have been involved. Women have been exposed to various kinds of health education. The St. John's Medical College Community Health Department for example, has been very involved in Dommasandra; they have helped foster people's demand for better health there.

The extent to which "women's health in women's hands" holds depends on the extent to which women have been empowered; thus, different areas will be at different levels of development with respect to health.

However, I do not think that health education given in two days or five days or even one month is going to make a great impact. This is a long-term process; the impact will be observable only after a considerable lag. I would like to congratulate the KMIO group on the concept and the process although none of their findings are statistically significant. However, the process of

initiating these activities and experimenting with different approaches within the PHC infrastructure is important.

Overall, the presentations and discussions during this session addressed some key aspects of the position of women's health and women's access to health. The role of poverty was highlighted not only in terms of the cost of seeking medical care, but also in terms of the absence of basic facilities, women's lack of time and women's overwhelming work burden. Psychological factors also contribute to women's reluctance to undergo screening. The results of the KMIO project have suggested that a great deal is possible when there is a commitment and motivation to change the current scenario. However, the project has also shown that commitment and motivation alone are insufficient in the context of limited and inadequate infrastructure.

Provision of basic facilities and high quality care must be ensured to meet the demand generated by mobilising women to seek health care.

7.3.2 Discussion outcome

- Health education cannot simply provide facts about illness, but must also attempt to change perceptions of the body, particularly the body "below the waist".
- Commitment and motivation alone are insufficient in the context of limited and inadequate health infrastructure. Provision of basic facilities and quality care must be ensured to meet the demand generated by mobilising women to seek health care.
- Despite the limitations of the project, one can conclude that committed and motivated rural health workers are key players in any effort to promote health awareness and to provide health services at the local level. The Junior Health Visitor can be trained to do the visual inspection test. The anganwadi worker can be used to give health education to population with which she is involved. The lady medical officer can be trained to deliver screening, treatment, and referral services at the PHC. Vital information on cervical cancer must be presented to local level health workers in such a way that they grasp the importance of early detection.
- The constraints that village health workers face such as lack of accommodation in their field area, lack of transport, and lack of medicines must be urgently addressed.
- Both the empowerment of women and the education of men are required.
- One way of directly reaching local women (other than through village health workers) may be through the use of techniques like Participatory Rural Appraisal (PRA). Women's groups can be formed to discuss issues such as the prevention and control of cervical cancer. They can function as local monitoring groups to ensure that the government health infrastructure is accountable to women.

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- The process of creating demand for screening services and ensuring their utilization should not be the sole responsibility of health workers.
- The extent to which "women's health in women's hands" holds depends on the extent to which women have been empowered.

8. DOWNSTAGING CARCINOMA CERVIX IN THE INDIAN CONTEXT - PHASE II: NON-GOVERNMENTAL ORGANIZATIONS - A CATALYTIC ROLE IN THE EARLY DETECTION OF CANCER CERVIX

8.1 Description of the study

Two non-governmental organisations PRAXIS, Devanahalli and ADATS, Bagepalli, were willing to collaborate with us. Their area of work permitted introduction of these activities, and their location was sufficiently close to Bangalore so as to permit accessibility to the team at KMIO. The Primary Health Centres in these areas were identified. The details of the activities and the involved personnel are given Table 4.

Table 4. Project activities and involved health personnel

		NGO Area 1	NGO Area 2
Activities in the Field	Health Education	Female Junior Health Visitors* (JHV); Male JHV; Block Health Educators; NGO health workers	Female Junior Health Visitors* (JHV); Male JHV; Block Health Educators; NGO health workers
	Visual Inspection	Female JHV	Female JHV
Activities at the PHC	Visual Inspection	Lady Medical Officer (LMO)	LMO

* Previously known as Auxiliary Nurse Midwives

All health personnel involved in imparting health education underwent a one-day health education training session at KMIO. All health personnel who were responsible for doing visual inspection (VI) underwent a two-day training session at KMIO. They were taught to note the appearance of the cervix (its colour, shape, size, surface, the presence of any discharge or bleeding), and based on this, to decide whether the cervix was normal, abnormal or suspicious of malignancy. They were also provided with kits that contained the same equipment made available in the earlier phase. However a copy of the recordkeeping was made available to the NGO so that they could contribute to reduce noncompliance.

The referral process and treatment guidelines used in the field are given in Table 5.

Table 5. Referral process

	NGO Area 1	NGO Area 2
Female JHV	VI* result: referral to PHC if cervical abnormalities seen or suspicious of malignancy	VI result: referral to PHC if cervical abnormalities seen or suspicious of malignancy
LMO	Repeat VI Refer to KMIO if malignancy is suspected.	Repeat VI Refer to KMIO if malignancy is suspected.

* Visual Inspection

All women who reached KMIO as a result of referral from the PHC underwent visual inspection. Women would register with the Hospital Cancer Registry, if a lesion was visible, and receive treatment. Women would register in the Department's dysplasia clinic, if no lesion was visible and undergo further investigations (such as Pap smear, colposcopy, etc.).

The number of women reached with health education in the NGO study areas is impressive when one considers the time period i.e. 5 months when compared to 24 months when only the government health infrastructure was involved (see Table 6). The government health infrastructure had to impart health education and deliver services. The NGO had to only deliver health education and convince the women that the test was available at the PHC and that they should not just avail of the facility but also *if necessary demand the facility* when it was not offered to them. More than twice the numbers of women were screened by visual inspection in the two NGO areas when compared to that undertaken in all the intervention areas in which only members of the government health infrastructure were involved. Nearly the same numbers of women were reached with health education (2029 in the two NGO areas compared to 2235 in the four PHC areas).

Table 6. Number of women age 35-60 years reached by interventions

	NGO Area 1	NGO Area 2
Women reached with health education	680	1349
Women screened by VI in the field	657	1337
Women referred to PHC for screening who in fact were screened	31	0*

*No LMO available at the PHC.

8.2 Perspectives

8.2.1 An NGO perspective: PRAXIS

PRAXIS is an NGO working in Devanahalli Taluk, Karnataka State. It has been working in villages primarily to educate and organise the rural poor. One focus of the organization has been health education (rather than health care). The communities that PRAXIS works with have been divided into four mandals; each mandal has a women's group which discusses issues of local interest, including health. It is in this context that information on cervical cancer prevention and treatment were introduced to women.

Members of the KMIO project held educational sessions on cervical cancer for NGO staff who in turn spoke with women in the communities they worked with. The aim was to create awareness among rural women about the possibility of having cancer cervix, and the importance of early detection. Women were encouraged to approach the PHC for the test.

Two important problems were faced during the implementation of the project. First, a number of women were turned away from the PHC when they approached it for the test. Second, it was difficult to motivate women to go to PHCs for examination. Mr. Tuscano felt that this was in part due to the status of women (and women's health).

> *We analysed the family's expenditure on medical services, and there we realised that women, who require greater attention as far as health care is concerned, spend very little on their health care. Much more attention is paid to the men.*

Women in addition, were reluctant to speak about their health. PRAXIS staff stressed the importance of talking about women's health during group discussions.

The PRAXIS programme with the help of KMIO, has brought about a totally new perspective on health among women; in addition, men are also beginning to recognise the importance of paying attention to women's health. Women have realised that it is possible to talk about gynaecological problems and seek medical care.

8.2.2 The KMIO perspective

Evaluation of the research project undertaken by the Department of Gynaecologic Oncology at KMIO revealed that although the JHV could do visual inspection of the cervix to detect cervical abnormalities, it was difficult for her to find the time to impart health education. This led to KMIO approaching the non-governmental organisations, that have a rural infrastructure to spread awareness about cervical cancer.

The Department of Gynaecologic Oncology, KMIO, approached ADATS in Bagepalli Taluk which has about 228 villages, and PRAXIS in Devanahalli Taluk with about 277 villages. Both were interested in this attempt to examine the role NGOs could play in the early detection of

cancer cervix, specifically by educating women and motivating the government health infrastructure to provide screening services.

The Department trained health workers in PHCs (JHVs, LMOs, and male multipurpose workers) in visual inspection of the cervix, and provided information to NGO staff on cervical cancer prevention, diagnosis, and treatment. The NGOs were charged with imparting health education regarding the importance of prevention, the advantage of early detection of cancer cervix, and the need for complete treatment and follow up. A special emphasis was laid on the fact that better therapy results could be obtained if treatment was obtained at early stages of the disease. The NGOs were thus responsible for motivating rural women to seek cervical cancer screening (by asking the JHV to examine them during visits to the village).

A comparison of the number of women reached with information on cervical cancer and the number of women examined in the respective areas of both the projects shows that a great deal was achieved during the five month duration of the NGO project. When women were referred to KMIO for treatment, the NGOs would in addiiton ensure that women actually reached KMIO. According to Ms. Kalpana:

> *I think all those women who would not have reached KMIO due to financial and other problems came to us only because of NGOs. . . So, we at KMIO, feel that NGOs are the alternative models for the outreach of effective health services to the rural population.*

8.3 Discussion

8.3.1 Discussion issues

(a) The training received by PRAXIS from KMIO

Q: I have a question on the methodology that you used. Did your workers act praxis receive the same kind of training that the JHVs received from KMIO?

A: (Mr. Tuscano): We received basic information on cancer cervix: that it is important that women be examined; that if some abnormality is detected, it can be cured. So the one message that we got is that cancer is curable if it is detected early enough. Our role was primarily to motivate women to go for the examination, rather than examining women. From that point of view, that little information was sufficient.

A: (Dr. Vallikad): The training given to the NGOs is the same training that was given to anganwadi workers, block health educators, and all those whose responsibility was to impart awareness. The training was completed in one day. Thus, if it is somebody who has to impart awareness, it's one day training; if it's somebody who has to examine the patient, it's two days.

We really could not give a longer period of training. Health workers were trained for one month in the Chennai study. At the Institute for Cytology and Preventive Oncology, in Delhi study, they conducted the training over three months. They observed an 81% agreement between the

findings of the JHVs and the doctors. As a result of two days here, we got an only an agreement of 61%. We may have had better results if it was possible for us to conduct a reorientation for health workers, but the project duration did not permit that.

(b) PRAXIS' approach to health education

Q: So then, how did you go about it? Did you have women's groups? Did you have discussions?

A: (Mr. Tuscano): You see we have already in all our villages, women's groups, women's sanghas, and they undertake, many activities. Therefore it became very easy for us - since we have also been giving training to them on preventive health. So to add this component in our health education was relatively easy.

Q: Could you say a little bit more about your preventive health programme and how this component [on cervical cancer] - you said it was relatively easy to add this as a component - was introduced?

A: (Mr. Tuscano): Actually we have divided our entire area into four mandals, and every Wednesday we have women coming to our training centre. Each week women from one mandal come to our place. We try to discuss the basic problems that they face. From there we start to explain what those problems are and what are their causes. We talk about health problems, particularly women's health problems. We emphasise that the majority of health problems that are preventable, and we explain how to do that.

(c) Women's awareness of health issues and the impact of the KMIO project

Q: When you asked women about their health problems, did they tell you about their health problems are or did they tell you about their family's and children's health problems (given that there women do not give priority to their own health)?

A: (Mr. Tuscano): They never talk about their health problems nor do they talk about their children's health problems; they talk about the health of society and in this context, they may talk more specifically about health problems.

A: (Dr. Vallikad): When women come to KMIO, they are often stinking; occasionally they are dribbling urine. However, many never talk about their discharge; they say they have backache, stomach pain, or headache. We have to make detailed enquiries to ascertain try and get that important remark from them - to say that they have a white discharge or bleeding.

A: (Mr. Tuscano): But I think there is now a tremendous change. Since we took up cancer of the cervix as an important issue to be discussed with women, women have developed greater courage or openness to talk about it. They have realised that this could lead to very serious problems and so, if they get white discharge which is probably not serious at all, they would come and ask,

"Madam, this is my problem, you talked about white discharge, can I go for a check up?"

So theere is a change of attitude among women.

Q: I would like to know from your experience of working as an NGO within this intervention project whether you have been able to activate the health care delivery system (the PHC)?

A: (Mr. Tuscano): We concentrated on health education. Another important aspect that we tried to see was that all the PHCs in our neighbourhood carried out their responsibility to attend to the health problems of the people. We have for instance, developed a very good rapport with the doctor at the major hospital that is there in Devanahalli. There are certain situations in which the PHCs did not function too well. We tried in those cases, to make people demand these services from the PHCs. **Thus the only way we can function is by getting people to demand these services from the PHCs.**

At one time people could not think in terms of getting appropriate treatment at the hospital at Devanahalli. We routinely take at least four or five morchas every year and those morchas go in front of the doctor's house; so he realised that there is a force developing among the weaker sections of people. He also realised that he had to give the correct treatment, whenever required, to these people, as otherwise they would react. Thus mobilisation of people has made an impact on some of PHCs.

(d) Ensuring women's access to resources to seek medical care: the role of transportation

Q: The presentation raises a great deal of issues, and the conclusion that you came up is that NGOs may be alternative providers. This I think raises an enormous range of issues which we would probably need to discuss. One core issue the presentation raises is whether this can be taken forward to a higher scale. Here, we are talking about one or two NGOs that you have been working with. What would be required if this were to be done on a much larger scale which is what is implicit in saying that it is an alternative model?

For example, one thing that was mentioned was that when it came to referrals to KMIO, the NGOs themselves provided transportation. Now, obviously there is cost involved in there. How are those costs met? Clearly the NGOs themselves are meeting it out of their own funds. But, in that case, there is an implicit subsidy coming from somewhere, which clearly has to be addressed if one is going to talk about this on a much larger scale.

A: (Mr. Tuscano): As far as we are concerned the results of the study are not that spectacular, though relative terms, they may be better. We did not offer anybody transport and other facilities. The Bagepalli NGO did because Bagepalli is relatively far away from Bangalore - 96 kms. I do agree that a subsidy is involved. My question is, should the government not offer that? My basic question has to do with how much the government is willing to spend for 100,000

women who could be prevented from getting cancer as compared to a few hundred people who will die of cancer. So it is clear that we definitely require some amount of subsidies.

A: (Dr. Bhoomi Kumar): We have some experience in this area in connection with referrals for other health problems. Whatever funds are available is given to the village health committee, which decides who needs, money for transport, for referrals for surgical problems and so on. So there are strategies that have been worked out in different projects among NGOs to meet costs. The government should be involved, for example, I think in Tamil Nadu, the government gives free bus passes for cataract surgery. Also Central Government institutions allow people with leprosy to travel free by train for rehabilitative surgery.

A: (Dr. Mala Ramachandran): There are a lot of discussions going on in Karnataka now, about the action plan to be prepared for promoting women's reproductive health. There this problem of how transportation can be worked out was raised. So I think tomorrow when the policy makers are here, this should be raised; the issue of whether free bus passes or some sort of subsidy could be given to women who have been referred for diagnosis and treatment could be discussed.

A: (Ms. Reena Alexander): There is a very vast difference in the level of investment in health infrastructure in rural and urban areas. That is the context that we are talking about. I am afraid we are trying to promote a kind of double standard, one for the rural areas where NGOs do the work and one for the urban areas where there is more and more super-specialty, modernised allopathic health care.

I think the issue we are really talking about is allocations, health care allocations in rural areas. This means that more PHCs need to be set up; PHCs should reach the remotest villages and rural men, women and children should have access to health care. I think this is what we have to make an issue today. Whether NGOs have a role in making that access possible is an issue that needs to be discussed.

(e) Ensuring women's access to referral services

Q: I keep noticing that the majority of villages covered in the KMIO study are in or around Bangalore, say one or two hours journey from Bangalore. The experiences that have been described indicated that people were finding it difficult in reaching KMIO from such a near place. I was wondering about people living in Bidar or Bijapur or Dharwad who are, say, 400-600 or 800 kms away. Even if we succeed in identifying health problems there, even if we train the anganwadi workers, JHVs, or LHVs in identifying early stage cervical cancer, will we be in a position to reach out to those ladies after having identified their problems?

A: (Dr. Vallikad): We undertook this as a study, in addition to our regular hospital work. So we had to choose areas where we could leave in the morning and come back in the evening. Now the idea is that if we have to "metastasise" to other parts of Karnataka, which is the reason why we have called for this meeting, the strategy would have to be slightly different. The role that

KMIO plays will have to be played by other organisations that are closer to that particular area. Those other organisations could be private or governmental; all that KMIO can do is to train them to perform the same role that KMIO does here.

(f) Accountability

Comment (Ms. Ammu Joseph): I have two comments to make as somebody who is neither GO nor NGO. One is that I feel it is important not to assume that all government health infrastructure is bad, and that all NGOs are good. There is a huge question before us today about the accountability of NGOs. Second, there is a tendency to assume that social and other services can reach people only through NGOs, or best through NGOs. We hear a lot about this both from governments and donor agencies these days. I feel it is really letting government personnel off the hook. Why are they employed if they cannot do their jobs? We all know how much of public funds go into the upkeep of government employees; can we not legitimately expect performance from them? There are examples of government institutions with government personnel working effectively. Why can we not expect the same from all government institutions?

8.3.2 Discussion outcome

- The PRAXIS programme has demonstrated that it is possible for women to talk about gynaecological problems and seek medical care. It has also shown that men are beginning to recognise the importance of paying attention to women's health.
- The role of PRAXIS was primarily to motivate women to go for the visual inspection test, rather than to provide visual inspection services. PRAXIS was responsible for communicating the following message to women: that cancer can be cured if it is detected early; that a simple test, that is visual inspection of the cervix can detect cancer at an early stage; and that visual inspection services are available at the PHC. PRAXIS divided the area in which they worked into four mandals. Once a week, discussions were held with women from a particular mandal, to discuss the basic problems faced by them. During these meetings, it was emphasised that the majority of health problems are preventable, and many like cervical cancer can be treated and cured if detected early. A tremendous change in the attitude of women was observed after these discussion programmes. They developed the courage to come and ask

  "Madam, I have the problem of white discharge, can I go for the check-up"

- Other NGOs can take a similar approach.
- Thus it is easy to add cancer cervix prevention education to the other activities of various women's groups that already exist in villages.

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- A one-day training session for individuals involved in health education efforts and a two-day training session for individuals involved in performing visual inspection reasonable. Longer periods of training are not logistically feasible.
- Although the personnel of the health infrastructure could perform visual inspection of the cervix to detect cervical abnormalities, it was difficult for them to impart health education. The NGOs who have a grassroots infrastructure are in a better position to spread awareness about cervical cancer, and can thus complement the efforts of the health infrastructure.
- The number of women reached by health education by the NGOs in their areas was larger than the number of women reached by health education in the areas where this was the sole responsibility of the health infrastructure. The experience in the NGO areas proves that a partnership between grassroots organizations and the health infrastructure is possible.
- The NGOs can mobilize people to demand health services in communities where PHCs do not function well. This strategy did have an effect on some PHCs in the NGO areas.
- The NGOs also attempted to ensure that women in whom a cervical abnormality was detected reached KMIO.
- The government should address infrastructure issues such as availability of lady medical officers in PHCs, provision of transportation allowances for seeking medical care, etc.
- The role of KMIO will have to be played by other similar organizations if this concept has to be extended all over India.

SECTION III

LESSONS LEARNED FROM COMMUNITY-BASED PREVENTIVE HEALTH PROGRAMMES - IMPLICATIONS FOR EARLY DETECTION OF CANCER CERVIX

9. THE FRCH EXPERIMENT: COMPREHENSIVE COMMUNITY BASED HEALTH CARE

9.1 Description of the study

As underscored by Mr. Ghosal, Additional Secretary, Government of Karnataka there, is as of today no detailed operational model of health care in the Panchayati Raj which aims to promote decentralisation in the planning and implementation of health programmes. Vertical structures, rigid targets, mismanagement, and low motivation of health personnel limit the current health care system. There is little reason to believe that this situation will change with the mere input of additional monetary resources or increased medical practitioners flooding rural areas. It is said that the only alternative is to have more PHCs and more doctors. The aim of FRCH's project (the focus of Dr. Nergis Mistry's presentation) was to find out through research whether such an alternative is possible and feasible.

Several projects and studies undertaken in the last two decades have demonstrated the ability of workers to achieve the grassroot level targets laid down by national disease control programmes. Therefore, technical training of sorts is possible for rural or urban lay persons. The cadres of JHVs prove it. What makes the alternatives under the Panchayati Raj system different from the existing health care system is that they seek to infuse accessibility and accountability into the system, in addition to building a relationship of trust between health care providers and users.

The corner stones of the FRCH initiative are - concern for women's status, promotion of self-help at the grassroots level, and seeking of solutions through appropriate technology. The overriding objective is the systematic exploration with detailed operational recording of the role that village women can play in their community's welfare, given their enhanced political representation in the Panchayati Raj. The idea is not just to vocalise their problems, but also to demonstrate their ability to use available resources, knowledge, and technology in the various fields that encompass their development, one of which is health.

The project is being conducted in the Parunda Taluka, approximately 50 kms from Pune. The villages are reeling under inflationary pressure of urban markets; there is very low employment, and people's access to basic needs such as education and health services is extremely limited.

The community health care model forms the structure of the project; a population of approximately 30,000 is covered. The key functionary currently envisaged at the community level is the senior thai or aunt for a population of 1,500. Sixteen thais are needed to cover the entire project area. Each senior thai will be trainer, motivator, coordinator and referee for four junior thais. Each junior thai will serve a population of about 350. Project personnel will train senior thais; junior thais and traditional birth attendants will be trained by senior thais.

The key criteria for selection of senior thais were motivation, acceptability by the community, financial support, and adequate literacy (in decreasing importance). Educational qualifications and socio-economic status get low priority. Community groups such as gram panchayats, gram sabhas, mahila mandals, youth organisations, and taluk mandals need to be sensitised and involved at every stage of the project. They should be clearly informed of the objectives of the exercise, the role of the NGO itself (because there is no reason why all NGOs should be trusted), and the withdrawal of the NGO after completion of the project activities in due course of time.

Names of potential candidates were elicited from gram sabhas, mahila mandals, and through delicate indirect questioning of the community. The initial community-based selection was followed by a formal interview by FRCH investigators, which laid out the terms of the project, the expectations, the level and mode of remuneration (through village panchayats), and the existence of performance evaluation. The process of selection should be made open to the community. Ideally, the evaluation of the village level functionaries should be an open process conducted by a committee including representatives of the community.

The main components of the training included technical skills, communication and leadership skills, and maintenance and managerial skills. The training sessions were conducted initially in a semi-formal atmosphere, using participatory methods such as discussion, khelwadis (non-formal education forums), role-plays and demonstrations. The content of the training sessions included health education, watershed management, essentials of rural banking, and most important, public information. There was an emphasis on health not only because of its centrality, but also because it served as a mechanism by which trust could be established in the relationship between the community and the NGO.

Health training initially involved activities such as utility maps, soliciting of symptoms, diagnosis, and referral. The second phase concentrated on emergency medical care (important in remote areas), on reproductive problems with which the thais could easily identify. Simultaneously, a referral system and a local laboratory run by village women to undertake simple investigations of women's health such as anaemia, pregnancy testing, urine albumin, etc. were built up.

The community's confidence in a health programme depends to a great extent on the effectiveness of the clinical services that are provided. The main objectives of clinical management of reproductive tract conditions will be to diagnosis and treat problems; to provide counseling to

initiate behavioral change; to encourage and support treatment of index cases and contacts; and to screen for related conditions, one of which is cervical cancer. Surveys to collect epidemiological data will be avoided; rather, information will be culled during provision of diagnostic and curative services at the local level.

It is important to recognise that although individuals in the community are trained in basic health care provision, they are likely to share the cultural viewpoint of the community. Thus, periodic assessment of perceptions of health providers at the village level is required. Open-ended discussions rather than structured questionnaires were used due to the sensitive nature of the issues of concern.

These discussions have been revealing. Though illiterate, life's experiences have made them savvy in many aspects. Paradoxically, knowledge about the body, specifically of the lower orifices, is particularly poor. Many felt that the baby was born from the urinary tract. The prime luxury that all women wanted was a bath; many have had no baths for at least several years, and most did not know what their bodies looked like. Women thought that men had a uterus that is closed; so, they recognised that men could also be responsible for infertility. They were aware of cervical cancer, and the mortality associated with it.

White discharge was experienced by all, but none felt that it merited attention or treatment. None linked it with reproductive tract infections; however, it was linked to tension, weakness, infertility, and consumption of tamarind. The most commonly perceived illnesses were tension, depression and weakness which women attributed to hard labour and little food.

It is hoped that this project with its careful attention to process documentation will help measure human resources, technology costs, and operational problems associated with decentralised health care systems. A key determinant of the success of such an initiative will be the availability of financial resources at the grassroot level.

9.2 Discussion

9.2.1 Discussion issues

(a) NGOs' role in health: creating models or duplicating structures?

Q: You are talking about setting up referral services and things like that. Are you concerned about replicating government services? You talked about setting up labs so that they could screen for anaemia. That's supposed to be done in the PHC (if there is one in the area you are working in).

A: (Ms. Nergis Mistry): At the moment our project would be a sort of substitute for government services, because they are not functional at that level. How this can be gelled eventually into the government system would have to be thought about.

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Q: (Dr. Shobha Raghuram): Nergis, you ended your presentation with the question of getting resources to the grassroots level. Now our concern which has been echoed by both Saraswathy, Ammu and Gita as well, is that you have the Eighth Five-year Plan outlays in which there are budgets which are specifically meant for health right from district to primary health care centres. Our concern is that a good bit of this, at least if you take Karnataka, goes under-utilised or non-utilised; people are not even getting the 25 essential drugs that are mandatory as a citizen of this country, in the PHC. So there is a real problem here, and I think the issue of advocacy which came up yesterday is very important. We feel that NGOs must be able to launch major advocacy campaigns which people like Dr. Antia really have.

Now the concern is that if you are setting up systems, which work better than PHCs what happens to the major financial and human investments, made in those PHCs? What's happening is that scarce financial resources tend to get duplicated, and the rest of it goes into what Ammu calls 'extreme pockets of absolute unaccountability'? So we wondered if you had thought about this? What really is the solution because there is a pressing issue - people need that medical care.

A: (Ms. Srilata Batliwala): I am going to try and respond to this as an alarmist of FRCH. This is a very important question; it's a question that the Foundation for Research and Community Health has been alive to since its inception in 1975. Do you meet the needs of the people or do you pressurise the public health infrastructure to deliver the goods? At that time, we were still quite naive and inexperienced. We were posing it as an either/or kind of situation when it really was not. As far as FRCH is concerned, whether in this project or in its earlier projects, *the approach finally was that there is no question that, public services must be made to deliver the goods to people.*

And there is no question that people must be mobilised using whatever strategies are feasible to place that pressure on the system to deliver the goods. However, even if the system can be pressured to deliver the goods, what kind of goods should it deliver? This is not always very clear cut. So I think FRCH's role has been to try and develop a model, a design, where you try to develop the most appropriate set or mix of services, which then serves as a basis for advocacy.

One very important aspect of every FRCH experiment has been very careful monitoring of costs because that is usually one ground on which you lose with government. They say, "No, this is too expensive. You know we have Rs.3 a year per woman for reproductive health and we can't deliver this." The public health budget for a taluk in Manwar, was Rs.7 a year; it was shown that in Rs.7 a year a full range of basic health services could be delivered. So what such experiments are doing is developing a basis for advocacy; they say, *"Look, don't tell us you cannot do it; this is how to do it. These are the components; these are the resources; this is the technology, and this is the training that it requires."*

(b) Making community health projects sustainable

Q: During your presentation you talked about withdrawal of the project. Could you tell us a little bit about the actual mechanism? I mean how do you really decide time wise, and how do you really dismantle and leave things in place and go on to the next part of the programme?

A: (Ms. Mistry): We have clearly communicated to the gram sabhas, the gram panchayats and the mahila mandals and the people whom we are training about the withdrawal. The basic question of withdrawal comes in the process of remuneration particularly. At the moment there are no financial resources that can be raised at the village level for training and activating village level personnel. What the Foundation is doing now is to put in the money for their training, but the important thing is we don't pay the health functionaries ourselves; we pay it through the village. Gradually, the village will have to raise its resources if they find the activity worthwhile either through advocacy at higher levels or through their own local situation.

9.2.2 Discussion outcome

- Community-based health projects have to decide whether they are going to meet the people's needs or whether they are going to put pressure on the public health infrastructure to satisfy people's needs. The FRCH has attempted to develop a model based on combining the two approaches: providing a specific set of services and serving as a catalyst for advocacy.
- Sustainability of community initiatives must be addressed. Initially funds can be channelled through through village administrative bodies for community projects. In due course, the community will have to raise its own resources if they find the activity worthwhile. This can be either through government agencies and programmes or through community fund raising.

10. LESSONS FROM A LEPROSY ERADICATION PROGRAMME

10.1 Description of the study

The focus of this presentation was the Rural Health Research Project run by the Foundation for Research and Community Health from 1975 to approximately 1985 with which Ms. Srilata Batliwala was associated. The presentation was an analysis of the leprosy eradication programme that FRCH conducted in its Manwar and Uran health project areas, and its relevance to the control of cancer cervix.

10.1.1 Leprosy and cancer cervix: the commonalities

Both diseases are associated with a deep psychic fear. Leprosy, culturally, has a long tradition of being an extremely feared disease. We can say that cancer of all kinds, while it may not have

the same cultural and religious connotations, is also a deeply feared disease. These diseases are believed to be incurable. Basically cancer means death, and leprosy means disfigurement and isolation. There is a tendency, as a result, on the part of anyone who might have it to hide it. This is aided and abetted by the fact that both diseases often first appear, and certainly cancer cervix, in unseen areas of the body. You often, for instance in the case of leprosy, get a hypo-pigmented patch on the back. Some symptoms like white discharge are largely ignored or treated as normal in the case of cancer cerivx. It is quite easy to miss the diagnosis in both cases. Yet in both cases, early detection is absolutely critical, in the case of leprosy, to avoid disfigurement, and in the case of cancer to avoid death.

Both diseases are treatable and curable, however both have an important psychological component, and in the case of leprosy a social component as well which has to be dealt with. In both cases, when treatment commences, default rates tend to be very high because of the relief of immediate symptoms or discomfort. There is a tendency to believe that one is cured because the external symptoms have disappeared. These are the commonalities.

10.1.2 Leprosy and cancer cervix: the differences

There is a high degree of social stigma in the case of leprosy. Isolating the person, the sufferer, was a very common practice, and this was an important barrier to early detection. The common social reaction in the case of cancer, is one of sympathy and support. Leprosy is infectious though not highly infectious; cervical cancer is not. The treatment of leprosy, at least in the days of Dapsone, was low cost (five rupees a year); however, with cancer cervix, we are dealing with a higher cost of treatment.

The differences are much fewer than the commonalities. So, we are dealing with two diseases, which have a great deal in common. Thus, strategies that were used for early detection and treatment of leprosy may prove useful when considering approaches to the control of cancer cervix.

10.1.3 The FRCH project to eradicate leprosy

The Manwar project was initially set up in North Alibagh taluka along the Konkan coast of Maharashtra. Although geographically close to Mumbai, this area was quite inaccessible; in the 70s it took more than three and a half hour by road to reach Mumbai. A ferry service functioned during the non-monsoon months. A baseline survey conducted in 1974 revealed that very few people from these villages had ever visited Mumbai for any kind of medical treatment. Alibagh Civil hospital, which is at a distance of 50 kms, was the nearest source of medical care.

The Manwar project was funded largely by a private industrial foundation. The family running the foundation came from that area. A small primary health centre with ten beds was constructed. There was a B.A.M.S. doctor in charge of it; one nurse-midwife, two JHVs and 30 village health workers (VHWs) were selected and trained (through the same process described by Nergis). These were women who were generally in their later reproductive years or post-

reproductive years, and highly acceptable to the community. The remuneration they received was paid partly by the local panchayat samithi; Maharashtra did have a panchayat system of sorts at that time although not at the village level. The panchayat samithi agreed to pay half their salary. This was supposed to reflect the community's commitment to this programme. The rest was paid by the Foundation.

The approach emphasised domiciliary detection, education, treatment, counseling and motivation. The village health workers were given training. Leprosy was one of the subjects very intensively dealt with. During the training the problems of their own fears, superstitions and attitudes about the disease had to be addressed. The main approach was not to talk about this disease as leprosy (in which case not a single patient would be identified). So the approach was to say that there is a skin disease which can later lead to problems. So the word 'kushtaroga' was never used, it was always to deal with a desensitised hypo-pigmented patch. Since examination in the case of women, involved removal of the blouse, the fact that the village health workers were women from the same community and thus had a rapport with them, facilitated the process of disease detection.

After smears were taken, and the diagnosis was confirmed by the FMR in Mumbai, treatment was begun. Dapsone tablets for treatment, was obtained from the government. The Manwar PHC was treated as a government PHC as far as drug disbursement was concerned. Also an arrangement with the Directorate of Health Services ensured that the basic budget of a PHC would be given to the Manwar project, and PHC doctors were posted on deputation there. So the basic idea was to build on what would be the normal infrastructure of a government-run primary health centre, and to demonstrate that with proper accountability systems, with adequate drug supplies, with motivation and education, the same system can deliver the goods extremely well.

The project was a community health project with a strong preventive and promotive component. So, the focus was not just leprosy. Children were immunised; deliveries were conducted. A project ambulance made two scheduled trips a week to the civil hospital at Alibagh for referrals; thus, support was provided for people who needed to go to the civil hospital for referral services.

The project ran between 1976 and 1983. When it began in 1976, according to the National Leprosy Eradication Programme (NLEP) register for that area, there were less than 30 diagnosed cases of leprosy. Less than 10% were taking Dapsone. In one year (1976-1977), detection soared to over 100 confirmed patients. Over 95% were on regular treatment largely because the VHWs were dispensing Dapsone on a house to house basis. However, this scenario changed very quickly; within a few years, it became such that if the VHW forgot to provide Dapsone, somebody would remind her. *A demand was thus created when people understood the impact of the service on their health.* As of 1983 not a single new case was detected in the entire community because the pool of infection had been virtually eradicated. The individuals who

required reconstructive surgery due to advanced disease were provided services at J.J. hospital in Mumbai.

Five years after the project began, leprosy was no longer considered a stigma; there was much less anxiety talking about leprosy or saying that this is an early stage of leprosy. Thus, community beliefs were changed in a rather brief period of time.

There are three or four basic lessons from this experiment for the control of cancer cervix. First and foremost is the importance of a community-based holistic approach that deals with a whole range of people's health needs. A community-based approach should incorporate education, detection and diagnosis, provision of treatment, counseling of health workers, an understanding of the local culture, an understanding of people's fears. The second important lesson to be learned is that back-up services of reasonable quality and reliability are essential to make any community-based approach effective. The third relates to a failure of the Manwar project, that is, its inability to build up pressure to convert health into a genuine political issue which would enable people to mobilize and demand services even when the Foundation withdrew, as it indeed did.

The Foundation's goal was to withdraw within a period of ten years. What actually happened was that the Foundation was thrown out. This was, in a sense, a symbol of success because in eight years time the local panchayati samithi felt that they could run the programme. There was a lot of pressure on the Foundation to improve the quality of secondary care available at the PHC. People wanted an X-ray machine; wanted cesarean sections to be done at the PHC; wanted many more surgical facilities. It was felt that if the Foundation could not provide these facilities, the local leadership would do so. After the withdrawal of the Foundation, VHWs continued to function for several years, and were paid by the panchayat samithi. The lesson here deals with the image of good health care that has been created, and that has become the aspiration of rural communities. The image is one of a highly sophisticated curative hospital. People are not very willing to swallow the story about holistic approach and prevention and so on.

10.2 Discussion

10.2.1 Discussion issues

Replicating/extending NGO experiences

Q: (Dr. Gita Sen): The project, I would imagine, had two core objectives. One was to show that as a deemed PHC, if you put in the right inputs, did it the right way, you could deliver. It must have had another objective that is that somehow, somewhere the government would pick it up and start doing similar things elsewhere. It seems to me our key problem with this whole area of NGO/government interaction; NGOs as models; NGOs as experiments; NGOs as pilots; and so on is that this second objective just does not happen. We are not addressing sufficiently what it is that we need to do.

We put it broadly at the level of advocacy, and leave it at that. Advocacy can mean a million things, none of which may end up with the government figuring out how to get beyond its own paralysis. I wonder if there was reflection on this within FRCH or has been in terms of project learning over time about what might be done. More than the commonalities and the specifics of the technicalities of the diseases and the provision of services, to me, this is really the core issue.

A: (Ms. Srilata Batliwala): There were two replication effects that did occur, although the manner in which they occurred may not have been what we planned.

You must remember that at the time when the Manwar project was launched in 1974, there was really only one other project in India which had experimented with training village women as primary health workers, the Jamkhed project in Ahmednagar. I think that both the Arole's project and the Manwar project had a very strong impact on national policy.

When the new health policy of the Government of India was announced in 1978, just after the emergency, the village health worker became a part of the national health system. These village health guides (VHGs), (CHVs, etc. - all kinds of different nomenclatures were used) became a part of the stated policy of the Government of India. Every state was directed to select and train village health workers to be the primary health care agents in the village. They also specified that health workers should be women since the bulk of the burden of ill health is borne by women and children, and they are the most difficult population to reach. However, in Maharashtra, after this policy was implemented, we found that about 80-85 per cent of all the health workers, who were appointed were male. This immediately became one more job to hand out, and a major source of political patronage at the local level.

The second effect that it had was the setting up of the Maharashtra Government's immunisation programmes. There was a very detailed documentation of how the Manwar project achieved 100% immunisation in a period of five years. This strategy was incorporated into the Directorate of Health Services programmes in other districts. But there it ended.

I cannot answer the second part of the question that you have raised, but I think a major reason for this paralysis is the whole nature of the accountability mechanism within system. In any kind of NGO initiated programme, there is a very high degree of supervision, monitoring and accountability of the programme. Now what happens in government is that there's a selective incorporation of elements of your strategy, but not the whole framework within which that strategy operated. So they say, "Ah, village health workers. Jolly good let's have them." The whole set-up that facilitated and enabled them to work is not there as they became one more very convenient tier, to which family planning cases could be brought. So before very long, these workers who had been doing a whole range of services in the community just became family planning case agents. So I think there is this gap and I don't know how this is to be bridged.

Comment (Dr. Sen): I think the corresponding thing to the village health worker right now is women's groups: Mahila Swasthya sanghs, groups for everything under the sun, with very little

conception of what these groups are supposed to be doing. The assumption is that somehow you support the formation of groups and then everything is going to be taken care of.

Comment (Ms. Batliwala): I think the other aspect that is very crucial to the paralysis has to do with a centuries old tradition of dealing with quantitative elements. When you ask what is monitoring, what is evaluation or what is accountability, I think that in government, and I have been part government, the easiest thing to do is to monitor quantitatively. The tendency is to leave out the quality component because it's much messier. You cannot monitor it to the same extent; the DHO, the PHC MO cannot at monthly meetings say, "So, how many women have you educated on this?" or "How many attitudes have you changed on that?"

10.2.2 Discussion outcome

- Strategies that were used for early detection and treatment of leprosy may prove useful when considering approaches to the control of cancer cervix.
- The approach used in the FRCH project emphasised the eradication of leprosy through domiciliary detection, education, treatment, counseling and motivation. It did not identify the disease as leprosy (in which case not a single patient would have been identified). Rather, the initiative was based on talking about leprosy as a skin disease that can later lead to problems. One may want to use a similar approach in tackling cervical cancer, if there is a stigma attached to the name.
- Women from the same community, who have a rapport with other women, can facilitate disease detection in communities.
- The government health infrastructure can function effectively if appropriate accountability systems, adequate drug supplies, motivation and education of health personnel is ensured.
- Community health project should be broad-based with a strong prevention and health promotion components.
- Community health projects can create a demand for health services over time throughout the demonstration of the impact of services on people's health.
- Community beliefs and perceptions regarding disease can be changed in a rather brief period of time.
- Panchayats can sustain community health projects once demand for health services is created.
- It is important to include qualitative indicators in addition to quantitative monitoring of the government infrastructure (which is relatively easy to do).

(Contd.)

- Selective adaptation of elements of NGOs' community health initiatives is bound to fail. All aspects including supervision, monitoring and accountability systems should be incorporated in attempts to replicate these programmes.
- The following specific lessons can be drawn from the FRCH experiment for the implementation of cancer cervix prevention and control programmes:
  - first and foremost is the importance of using a holistic community-based approach, one which addresses a broad range of people's health needs;
  - second, a community based approach should incorporate education, diagnosis, treatment, and counseling;
  - third, sensitivity to and an understanding of people's needs, constraints, and fears should be the hallmark of the programme;
  - fourth, referral services of high quality and reliability are essential;
  - and fifth, attention must be paid to posing health as an important political issue in order to enable people to mobilise and demand services when the project comes to an end.

SECTION IV

CONCEPTS FOR FUTURE STUDIES

11 EARLY DETECTION OF CERVICAL CANCER: HEALTH CARE AND THE PANCHAYATI RAJ

11.1 The role of Panchayati Raj institutions in the early detection of cancer cervix

11.1.1 Background and Description of concept

The aim of Mr. Satish Chandran's presentation was to outline the three tiers of the Panchayati Raj institutions in relation to health care in general, and to cancer control in particular. The 73rd Constitutional Amendment has revived interest in Panchayati Raj institutions as a route to accelerated rural development and social transformation. However, these institutions operate under various constraints: legal, political and social. In order to appreciate the role of Panchayati Raj institutions in cancer detection, it is certainly necessary to appreciate the context in which these institutions operate.

The 73rd Amendment has a schedule, which lists functions, which can be entrusted to the Panchayati Raj institutions (all three levels: district, taluk, and village). This list includes hospitals, primary health centres and dispensaries. This broad framework provided under the Constitution in turn determines the functions entrusted to different institutions under the laws passed by each state. The Karnataka Panchayati Raj Act was passed in 1993; it lays out the functions of Panchayati institutions at all levels. The functions listed at the district and taluk levels are general; there is no reference to any particular disease. At the village level, perhaps most germane to the discussions here, there are two entries. One relates to the implementation of family welfare programmes, and the other talks of preventive and remedial measures in case of epidemics. The Karnataka Law also has a provision which says that gram panchayats may also carry out measures which are likely to promote the health, safety, education or social and economic well-being of its inhabitants. Thus, virtually, any kind of activity can be undertaken by the gram panchayat, provided it has resources to carry them out.

Subsequent to the enactment of this Panchayati Raj Act in 1993, the Government of Karnataka issued a notification in July 1994 listing the schemes entrusted to zilla panchayats and taluk panchayats (leaving the gram panchayats out) in much greater specificity. Forty two schemes have been identified under the zilla panchayats, one of which is cancer control. It is only here that a specific reference to cancer is found under the Panchayati Raj institutions. Cancer control figures along with leprosy, malaria and guinea worm control.

An important result of the July 1994 notification is that all the PHCs have been brought under the control of zilla panchayats. There are in addition, standing committees consisting of elected members at all three levels that ensure that the welfare of women and children is promoted. Both

these facts need to be kept in mind because they provide the statutory framework within which these institutions can play a part in the control of cancer cervix.

The July 1994 notification is important not only because it transfers functional responsibilities in specified areas, but also because it implies the transfer of funds to implement programmes in those specific areas.

Elected members of Panchayati Raj institutions can ensure that primary health centres function properly; that JHVs discharge their duties effectively. They in addition, can undertake other kinds of activities such as health education. They can in this way play an important role in a community-based approach for the control of cancer cervix. The crucial question is the priority these institutions are likely to attach to detection of cancer, noted Mr. Chandran:

> *Will this figure high in their overall list of priorities? My answer, to be very honest, is that it is unlikely to have a high priority. I would very earnestly submit that we must appreciate the environment in which these institutions operate.*

The primary goal of Panchayati Raj is to decentralise government, and hence, make more accountable and responsive to the needs of the people. Panchayati Raj institutions are also expected to be instruments for accclerating rural development. The bulk of funds available at the gram panchayat level are for employment generation programmes. The point of this discussion is to highlight the likely priorities of elected members of the panchayat system. The detection of cancer, or for that matter, the detection of any others specific disease is unlikely to be of high priority.

There are four potential ways in which elected panchayat members may be involved in cancer control. First, they may support efforts through their supervisory powers over PHCs and PHC functionaries. They may, for example, ensure that paramedical staff carries out their specified functions. Second, they may support NGOs that are interested in a particular aspect of health care like cancer control. Third, Panchayati Raj institutions can play a part in the dissemination of information and creation of awareness. This role may be enhanced by the fact that one-third of all Panchayati Raj members will be women. However, given the social milieu in which Panchayati Raj operates, one should not expect too much from women members.

> *As far as women and Panchayathi Raj are concerned, I would place priority on making sure that they are able to participate in the system effectively, making their presence felt, taking part in decision making, making sure that programmes intended for the benefit of women and children get their due share of funds and so on. If they were able to do that, and I certainly would say at present they are not always able to do that for various reasons, that itself would be a major change.*

Mr. Chandran concluded by saying that high hopes should not be pinned on Panchayati Raj institutions as far as control of cancer cervix is concerned:

As far as cancer control is concerned, the stimulation for these institutions to give their best to come forward and assist has still to come from the doctors and medical personnel in charge of cancer control. Without that initiative, without that initial stimulus, I do not think the Panchayati Raj institutions themselves will take any kind of lead. But if such stimulus is forthcoming, certainly some kind of synergistic results can be expected through the interaction of the medical personnel, the NGOs and the elected bodies.

11.1.2 Discussion

11.1.2.1 Discussion issues

Q: (Dr. Sen): I just wanted to ask you two questions. One is, you said, functional responsibilities of all the PHCs have been transferred to the zilla panchayats. Now, there is no direct role here for the gram panchayats. What do you see as being the implication of that for the ability to make the PHCs actually function in the way that they should be functioning?

A related question about the schemes: We know that most of the funds that have been transferred are all scheme-related funds; are the Panchayati Raj institutions relatively free to implement the schemes according to the way that they think appropriate? Or do they have to follow a very standard implementation prescription?

A: (Mr. Chandran): Well on the first question, the principle followed is the area of benefit. Since the PHCs serve not only one village, but a whole group of villages, responsibility for controlling them cannot be given to any single panchayat. This is the general approach to the functional demarcation at the different levels. Incidentally, I may mention that an expert committee is currently at work, reviewing the whole scheme. Personally, I would feel happier if the PHCs are brought under the control of the taluk panchayats that is more logical.

As far as the second question is concerned, the answer is, there are certain schemes like IRDP and Jawahar Rozgar Yojana where detailed guidelines are prescribed nationally. At one stage these guidelines were laid out from Delhi, and when such detailed guidelines are attached to the utilisation of those funds, the local institutions really do not have much freedom. I would say that if you look at the overall functioning of either the taluk panchayat or for that matter the zilla panchayats, even today, I should think that 90-95 per cent of their activity is still governed by the guidelines. The guidelines more often really become mandatory directions, and the area in which these institutions can themselves set a pattern, can pave a new path, it's still very restricted.

11.1.2.2 Study and Discussion outcome

Legally, gram panchayats may carry out measures that are likely to promote the health, safety, education or social and economic well being of its inhabitants. Thus, virtually, any kind of health promotion activity can be undertaken by the gram panchayat, provided it has resources to carry them out. *(Contd.)*

- All PHCs have been brought under the control of zilla panchayats. Thus, elected members can ensure that primary health centres function properly. There are in addition, standing committees consisting of elected members at all three levels, who ensure that the welfare of women and children is promoted. Both these facts need to be kept in mind because they provide the statutory framework within which these institutions can play a part in the control of cancer cervix.
- *Cancer control is included in the list of responsibilities of the zilla panchayats.*
- The crucial question is the priority Panchyati raj institutions are likely to attach to cancer detection.
- PHCs serve not only one village, but also a whole group of villages. Responsibility for managing them cannot be given to any single panchayat. The PHCs should therefore be brought under the control of the taluk panchayats.
- Elected panchayat members, in conclusion, may be involved in cancer control in the following ways:
  - they may support efforts through their supervisory powers over PHCs and PHC functionaries;
  - they may support NGOs which are interested in a particular aspect of health care like cancer control;
  - they may play a part in the dissemination of information and creation of awareness. This role may be enhanced by the fact that one-third of all Panchayati Raj members will be women.

11.2 The role of women panchayat members in creating people's health awareness

11.2.1 Background

It is extremely important to take into account and be sensitive to the living situation of women when attempting to raise awareness about cancer cervix. This was the crux of Ms. Suman Kohlar's presentation which was based on her experiences as a woman member of the panchayat system, Vice President of the Bijapur Zilla Parishad, and her association with a multipurpose cooperative society.

She observed that during the last elections, according to 73rd amendment of the Indian constitution, 33% seats were reserved for women in the Zilla, the Taluk and the Gram Panchayats. This resulted in 35,000 women being elected as representatives to the gram panchayat, 3,500

- 4,000 women to the Taluk panchayat, and 1,000 to the Zilla panchayat. As a member and office bearer of the Bijapur Zilla Panchayat she had been involved in many programmes devoted towards raising women's awareness of health and other social issues. She noted that np programmes till today had addressed such as why women get cancer cervix, what the preventive measures that can be taken, etc.

Bijapur is considered to be a very backward district in Karnataka for example Ms. Kohlar said that if one goes to women in Bijapur and talks about hygiene, their response would be that they lack even drinking water. Thus, before hygiene and cervical cancer can be tackled, women's basic needs such as access to drinking water need to met. In conjunction with such actions, adequate facilities to maintain personal hygiene should be provided.

Other barriers to cervical cancer prevention include women's lack of awareness about problems such as white discharge. She felt that women are unlikely to be aware about white discharge because most of them wear coloured clothes.

She recalled an incident in her village. A woman who had excessive bleeding was diagnosed as having cancer and was referred to a cancer hospital. Her relatives decided that since cancer means death it would be better to get her daughter married immediately, and started looking for a suitable groom. Ms. Kohlar observed that such a reaction of the relatives reflect the very real problems that we are likely to face in rural areas.

She observed that the personnel and organizations that can help in cancer control are:

- anganwadi teachers who could incorporate this aspect of health awareness as part of their regular work (i.e. during their regular working hours) especially when they organise parent's meetings.
- mahila kalyana kendras
- women who are members of the Bharath Scouts and Guides
- Medical Colleges (e.g. the Al Ameen college and some other colleges showed interest when the problem of health education was considered and they had assured that if they are informed about the day and venue of the camps, they could assist in this activity with their staff.)
- practitioners of traditional medicine
- Mahila Samakhya - is an organisation working extensively for women and also in the field of traditional medicine can be involved in creating awareness.
- gram panchayat members who are suitably trained

11.2.2 Discussion outcome

- Health awareness campaigns should consider the practical reality of the living situations of women.
- A number of village level functionaries can be involved in health education, such as anganwadi workers, mahila kalyan kendras, gram panchayat members, etc. However, all of them have to be suitably trained and motivated.

11.3 Experiences with Panchayati Raj and the government education infrastructure

11.3.1 Background and description of the concept

Ms. Nandana Reddy's presentation dealt with her experience with panchayats in Kundapur Taluk, South Kanara on the issue of education which may provide some lessons for the involvement of panchayats in cervical cancer prevention and control.

Ms. Reddy described the evolution of the NGO's project. The initial approach was, when government institutions were found to be inadequate, to set up structures in parallel to the government's (such as extension schools, health facilities). The limitations of this strategy were soon realised:

> *We realised that setting up this kind of parallel structure actually does not make a very large impact on the issue. It could become just an isolated experiment. The whole question of impact replicability and a spread effect became one of our major concerns.*

This realization resulted in a concerted effort to understand the government and its structure. The goal of the Gram Ashrama, the project in question, was to develop a more appropriate model of development than the one in place, specifically for children. It was felt that the place to begin was the Panchayati Raj system.

As part of this effort, the NGO collected information on issues of concern to children, women and men in villages:

> *The children's issues were very very basic issues like, "We cannot use this kind of pump and therefore, we cannot draw water from it; we don't have a bridge and so forty children cannot go to school from a certain village; we have a problem with the anganwadi, and if the anganwadi is half a day, then I have to stay back from school to look after my siblings."*
>
> *When it came to the women, there were some issues that overlapped with the children. However, the children observed some issues, which the women did not recognise. Issues that the women wanted were sex education; they wanted more empowerment in terms of*

being able to defend themselves, their bodies, etc. They wanted more information with regard to employment; with regard to independence and issues of that kind.

When it came to the men, it was always lighting, roads and improvement of the panchayat office, and issues of that kind, which were very very different. There was absolutely no overlap between the issues of the men, and the women and children.

The NGO felt that it was extremely important to make the child the centre of planning, and children's issues the centre of focus. The Panchayat Toofan Task Forces were established to ensure this. The Panchayat Toofan Task Force was set up at two levels: at the gram and taluk levels. The Grama Panchayat Toofan Task Force consists of members of the panchayat, the children's sangha, and representatives of other groups within the village such as women, youth, and minority communities such as tribals.

The Grama Panchayat Toofan Task Force was responsible for planning for the village with the only criteria being that plans should be justified in terms of their effect this on children. The taluk level task force (similarly constituted) was given the responsibility of identifying funds within planned and non-planned schemes, and other sources that could be given to the grama panchayats.

The first issue that was addressed was education. The main problems identified were low enrollment and high dropout rates:

If a child is not in school, the child is a potential child worker; is a potential migrant; and therefore becomes a problem that we have to address.

It was felt that the problem had to be tackled within the government education system. The first step was to establish rapport with teachers:

We achieved [a rapport] because we were already running centres [education programmes]. So we could say, "Yes, we also share your anxieties; we share your problems; we also know how difficult children can be; we also know how difficult text books are, etc."

A rapport with government officials was also established through the Panchayat Toofan Task Force.

Most important, a dialogue was established with children, and their views were explored during a workshop:

What we did with children was to ask them what they felt about our centres - the good and the bad points.. the children actually identified within these three [demonstration] schools what they liked and what they didn't like.

Following this a workshop with teachers from the formal education system was held.

> *First of all, we tried to create an environment of curiosity... The second thing was that we created a very informal atmosphere in the beginning where questions could be asked freely ... The third thing that we did very consciously was that we were there to learn from them [the teachers]. They were the formal teachers; they had been teaching for years; we were there to learn from them, not to teach them. And, finally, of course, what was required was the presence of officials.*

The outcome of this workshop was the teachers' "rediscovering" themselves and their roles. Problems in carrying out their roles were identified. Strengths and limitations of the system were discussed. In addition, teachers were appreciated for the work they do. As a result of this process, changes have been implemented in the schools' functioning. The Panchayat Toofan Task Force monitors the implementation. Noticeable improvements have occurred:

> *What this has done in terms of an impact is that the attendance has gone up to 98 per cent, even in the monsoon when the attendance normally drops to about 15 per cent. Voluntary enrollment has taken place for the first time. And the children who normally have not learned to read and write in four years, have learned to read and write in six months with this system.*
>
> *What is interesting about this is that, although the NGO is needed to be a catalyst in the initial stages (giving training and expertise in terms of resource people and method), the actual system is run by a task force which constitutes members of the panchayat and other members of the community.*

Ms Reddy concluded by elaborating on the role of panchayat members in health promotion:

> *I think the question that was raised about whether it is possible for panchayat members or the panchayat, given their existing level of information, participation, knowledge, etc., to implement programmes of this kind [that is, cancer control] is important. I think at one level, we grossly underestimate their concern, and we over-emphasise their lack of written knowledge or their lack of so-called formal skills. We also have to recognise, I think, that the panchayats so far have been dealing with issues that are very far from women and children. And the moment we raise issues that are of concern to women, and the women find that it is possible that through the panchayat, they can address these issues, the women themselves, irrespective of where they come from, or what their background is - whether they can read or write or whether they even understand how the panchayat works - they will start responding to these issues in a very strong way.*
>
> *When you are talking about issues related to health, for instance, and cancer cervix is an issue that is of deep concern to women if they only knew what was happening to them, I am sure that women in the panchayat would see them as a major issues, and participate.*

11.3.2 Discussion outcome

- It was felt that, if the problem had to be tackled within the government education system. The first step was to establish rapport with teachers. Teachers have been doing their work for years; we were there to learn from them, not to teach them. The outcome of this interaction was the teachers' "rediscovering" themselves and their roles. Problems in carrying out their roles were identified. These findings indicate the need for a good rapport, from the beginning, between NGOs and the government health infrastructure in order to address cancer cervix.
- What is interesting about this project is that, although the NGO is needed to be a catalyst in the initial stages (giving training and expertise in terms of resource people and method), the actual system is run by a Panchayati Raj task force which constitutes members of the panchayat and other members of the community.
- The panchayats are not currently addressing issues pertinent to women and children. However, the moment these issues are raised and women find that it is possible to address these issues through the panchayati raj system, they will start responding to these issues in a decisve manner. Cancer cervix is of deep concern to women. If women knew what was happening to them, it is certain that women in the panchayat system would consider cancer cervix important and participate in control efforts.

12. EARLY DETECTION OF CANCER CERVIX - HEALTH CARE AMONG UNDER-PRIVILEGED URBAN WOMEN

12.1 Background and description of concept

12.1.1 Urban reality

Prof. C. M. Francis described the grim reality of the urban scenario and special reference to the special problems of the under-privileged urban women.

He observed that in ancient India all health practices were private, and the first recorded instance of health being a state activity was under Emperor Ashoka. According to Dr. Francis, the most important influence on health recently has been commercialisation. This effect is in keeping with the economic trends observed in the country. The salient features of these economic trends are: privatisation and commercialisation (including health care), increase in the cost of services, burden of repayment of loans, and a decrease in government spending on social services, including health). He observed that:

> *Out of every Rs. 100 earned by the government only Rs. 70 was available for any spending in social services including health. There is also the suggestion that government subsidies in health, education and other social service activities be withdrawn.*

Recent social trends include progressive erosion of values, increase in breakdown of families, increase in violence both communal violence and violence, against women. The use of tobacco and alcohol has risen as a result of increasing urbanisation and marginalisation.

These social trends affect the very fabric of Indian society. He observed that though Prof. Stjernsward suggested that every effort be made to preserve the three generation family structure that still exists in India, it is necessary to observe that at present even the nuclear family structure in India is breaking up. Political instability and corruption are rampant. However, despite these disturbing social and political developments, there are positive trends such as the awakening of dalits, tribals and backward classes and the implementation of Panchayati Raj system.

India's low standing in the world is reflected in its ranking by the UNDP. India's position among 172 countries according to the Human Development Index in 1991 was 123, in 1992 was 122, and in 1993 was 134. India is also ranked very low in comparison with Finland and Sweden (first) for potential resources including human, mineral, etc. and to Australia (first) for health.

Poverty is the most serious problem that India faces. The World Health Report of 1995 has observed that: "The world's most ruthless killer and the greatest cause of suffering on earth is extreme poverty. Poverty is the main cause of reduced life expectancy, of handicap and disability and of starvation".

A report of the Ministry of Rural development, July 1993, (quoted by Shri S. Mahendra Dev in the Economic and Political Weekly, 19 August 1995) has observed that the Indian poor can be classified according to their income in the following manner.

	Groups by annual income	*Percent*
a)	Destitute (upto Rs. 2,265/-)	1.14
b)	Very, Very poor (Rs. 2,266/- to Rs. 3,500/-)	4.27
c)	Very poor (Rs. 3,501/- to Rs. 4,800/-)	12.95
d)	Poor (Rs. 4,801/- to Rs. 6,400/-)	24.68
e)	Above poverty line (Rs. 6,400/-)	56.96

These poor, he observed, do not benefit from various schemes such as the Jawhar Rozgar Yojana, etc.

The percentage of people below the poverty line in India is as follows:

Year	*Rural*	*Urban*	*Total*
1989-90*	33	36	34
1992-93**	42	37	40

* Pre-liberalisation ** Post-liberalisation

An important cause of poverty was unemployment. According to the Draft VIII Plan Midterm Appraisal, 1995, the number of unemployed was 17 million in 1992 and 19 million in 1994. This kind of unemployment affects women mainly. The Marg Poll, published in the India Today, April 1995, indicates that the recent changes in the characteristic of India's Population is reflected as:

65 million	The elite
180 million	Consumers
275 million	Climbers
150 million	Poor (aspiring)
200 million	Destitute

These figures, he explained, evoked different responses from two different audiences indicating different perceptions:

a) a group of people interested in community health said -

"150 millions - Poor (aspiring), 200 million - Destitute, how awful. What can we do for them?"

b) While two American businessmen from the health industry said -

" Oh! Here is a beautiful opportunity. Look at that - it is another U.S. - 180 plus 65 - 240 million people are here to buy our products."

The health of the urban poor is affected by various prevailing conditions such as overcrowding, industrial pollution, unsafe water, poor sanitation, and poor access to health information and health services. The health of the urban poor in seven slums was assessed in a study in Bangalore by various organisations including Women's Voice. They observed that some of the factors affecting health of slum dwellers are physical and social. Some of the physical factors consist of inadequacy in nutrition, availability of water, (safe water), sanitary facilities, toilets and shelter. Some of the social factors are poor community leadership and dynamics, psychological problems (e.g. alcoholism, depression, stress, anxiety) and poor health education.

All these factors affect the health of women. However, he observed that their health is also affected by their oppressed status. Women are responsible for domestic chores, caring for the sick etc. They have to face the problem of polygamy and very often the resulting violence and abandonment. However the positive trends that can be observed with regard to Indian women are increased education and a greater focus on ecological, gender and children's issues.

The problems of the urban health scenario consist of problems with nutrition and its related diseases; food adulteration; food security; inadequate water; water borne diseases; pollution

related diseases; resurgence of communicable diseases such as Tuberculosis, malaria, etc.; gender related diseases; increasing non - communicable diseases such as HIV/AIDS and others; addictions and substance abuse; disabilities and injuries; psychological and psychiatric problems etc.

The diseases affecting women consist of all common illnesses PLUS anaemia; malnutrition, gynaecological problems, backache (poor posture), depression, anxiety, stress, etc.

Thus, the World Development Report, World Bank 1993 observes that

> *" Higher female mortality and morbidity have been noted as powerful evidence of the severe gender based asymmetries in Indian society"*

The Health care facilities available in urban areas are the:

- Government (Local, State, Central) sector which includes the city corporation run urban family welfare centres, maternity homes, dispensaries, primary health units, the integrated child development scheme (ICDS), mobile clinics and referral institutions.
- Voluntary sector which has primary health care and hospitals.
- Private sector which has private practitioners, nursing homes and hospitals

Thus, on paper there are plenty of facilities, but the more important factors are utilisation which is influenced by availability, accessibility and affordability.

There are ethical issues involved such as:

Who gets what care?

What are our priorities?

How do we determine our priorities?

Who determines them?

How are the resources allocated?

Thus, there has to be a change in the allocation of resources. The demand for such a change can be created only if INFORMATION is available. The information must be accurate and disaggregated according to gender, location and income. Information should be collected on quality of life, diseases, services available etc.

An attempt was made in Alapuzha (Kerala) to organise neighbourhood groups in order to create awareness about the urban basic services for the poor (UBSP). They observed that women learn the importance of self-reliance, to stand together in difficulty, to analyse the socio-economic milieu and to identify and prioritize problems and find their own solutions. However this experience had some favourable circumstances: the women were literate, politically conscious, socially forward. They also had some income already and were not destitute.

Dr. Francis observed that when one considers health care one could remember the poem by Tagore in Geethanjali, wherein he says,

> *"When I tried to bow to thee - my obeisance cannot reach down to the depth where thy feet rest among the poorest , and lowliest and lost "*

And the attempt in health care should be to reach the lost.

John F. Kennedy in his inaugural address said,

> *"I dream of things that never were and ask, why not?"*

And as far as health care in India our attitude should be:

> ***"Why can't we do something better than what we have already been doing?"***

12.1.2 Scenario of health care facilities in urban areas

The area of Bangalore City is about 450 square kms. According to the 1991 census, the total population is 41.7 lakhs; women number approximately 19.7 lakhs. In the slum areas, the birth rate is about 30 per thousand persons, and the death rate is nearly 10 per thousand persons. The infant mortality rate is about 80 per thousand births. Life expectancy is about 59.2 years.

There are 464 slums in Bangalore with a population of about 8.51 lakhs; *about 19% of the total population live in slums.* There are 1.61 lakh households in slums, 68% of which are nuclear families. The average size of the slum household is 5.27. Nearly 35% of households in slums belong to the scheduled castes and tribes. About 33% of households speak Kannada; 34% speak Tamil; and the remaining speak Urdu, Telugu, and other languages. Six percent of the slum population have absolutely no access to water supply, and 21% have no access to sanitation and latrine facilities. Health education strategies need to take all these factors into account.

The health infrastructure in the Bangalore City Corporation area consists of 31 maternity homes and 37 urban family welfare centres. The Bangalore City Corporation runs 19 of these 37 urban centres, while the remainder is run by voluntary agencies. There are nearly 180 recognised nursing homes, and 1,100 clinics run by registered medical practitioners in Bangalore. There are around 800 beds in various City Corporation hospitals located primarily in or around the slums of Bangalore City. Maternity homes provide general health care in addition to pre- and ante-natal services. Apart from this, staff in urban family welfare centres carry on outreach activities; each centre caters to about 50,000 people. The urban centres have one medical officer, one lady health visitor, three JHVs, and a link worker (who is the link between the community and the centre).

The BCC has developed community groups in 30 slums in order to promote community participation. These groups consist of women from the community who form "SHE clubs." Dr. Mala Ramachandran described some of the activities of these women thus:

They participate in the process of asking for whatever their needs are as far as health and development activities are concerned. We give them a one-day orientation on the various national programmes; many of them came forward asking us to organise programmes on mental health, family health, counselling on alcoholism.

12.1.3 The development of a strategy for the early detection of cancer cervix among the under-privileged women of Bangalore.

The strategy that will be used to promote early detection of cervical cancer in the Bangalore City Corporation (BCC) areas will be to train BCC health personnel (at the field and hospital levels), and to link these workers with referral facilities. The process will begin by training all JHVs in the BCC. Maternity homes will form the first level of referral. Doctors in maternity homes will be trained in early detection of cancer cervix. The programme will be monitored at monthly BCC meetings. The project is being undertaken under the auspices of the India Population Project and is focusing on reproductive health (including cervical cancer, STDs and RTIs).

Surveys have shown that nearly 50% of people living in slums in Bangalore avail of the services of private practitioners. It is hoped that they can be involved in the programme as well. The BCC has cooperated with NGOs on other projects (such as the India Population Project). NGO collaboration in this project is, therefore, likely.

12.2 Discussion

12.2.1 Discussion issues

(a) Reproductive tract infections in the context of cervical cancer control

Q: Dr. Mala, you said the project was on reproductive health. Did you train the workers in identifying RTIs or STDs when they looked at the cervices?

A: (Dr. Ramachandran): We are starting from December and we plan to do so with KMIO.

Comment (Ms. Alexander): We have been talking about cancer of the cervix - while it is very interesting and very helpful, the more important issue facing us is the issue of STDs and RTIs. Various community-based surveys show that there is a high prevalence of RTIs.

Q: (Dr. Sen): Mine was practically the same question. You said KMIOis going to be doing the training for this also? But a two-day training won't do if you have to start doing RTIs and STDs as well, in addition to just training them to deal with the cervix.

A: (Dr. Ramachandran): It depends on what aspect of the RTIs are you looking for.

A: (Dr. Vallikad): I'm not as worried about RTIs as I'm worried about STDs and AIDS, as RTIs - reproductive tract infections - are something which we deal with in KMIO. Women come

with white discharge; we have a dysplasia clinic going. Not all of them have got cancer cervix; they have an infection, and we give them treatment. Though we advice the husband; the husband does not take treatment, and she comes back with the infection . ..

A: (Dr. Ramachandran): What we plan at the field level is that the JHV will detect - maybe symptomatically or by a general examination - a problem; she refers the case to the first referral unit which is the maternity home. For every two lakh population, we have a maternity home manned by a gynaecologist. So she treats the case there. If she feels it necessary, she refers the case to KMIO. But randomly all cases that are examined by the JHV, one copy of the details of which patient she has examined is going to be sent to KMIO for the purposes of monitoring. They in turn will randomly check some of the cases, to make sure that the JHV is not totally wrong in her concept or diagnosis, and to check on false reporting.

Comment (Dr. Elizabeth Gergan): I am Dr. Elizabeth Gergan and I am working in the urban slums of Bangalore under the Community Health Department of St. Martha's Hospital. I think this screening of women will be very good because we do see so much of chronic pelvic inflammatory disease and we have no idea what the percentage is of STD and AIDS. We could be sitting on a mine.

(b) Maintaining hygiene when conducting visual inspection

Q: Now, at the moment Bangalore is having this electricity problem and it worries me a little because if sterilisation of the specula (used to examine women) is not adequate, there is a risk of transmitting infection in our desire to find out early cases of carcinoma cervix or pelvic infection. Would it be possible for an allocation of kerosene, or some means of adequately sterilising these vaginal specula?

A: (Dr. Ramachandran): As far as our hospitals are concerned, the JHVs already have bins which they are carrying for immunisation syringes; so along with that we are planning to see that they carry some sterile gloves and autoclaved specula. At the hospital level we have generators; so, we have no problem at all. So the only thing is that the JHVs should be made aware during the training programme of the importance of not reusing the speculum.

(c) Feasibility of cervical cancer control in Bangalore City

Q: Are JHVs going to give health education about cancer cervix? At the present, JHVs and LHVs are only interested in reaching targets.

A: (Dr. Ramachandran): KMIO has come forward to give us the flip charts for each of the JHVs who are going to be trained so that they can do health education. Later they will have to organise these sorts of training programmes at the community level, for example, through SHE club meetings. We have to first have a series of awareness programmes, and only then can we start doing the gynaecological examinations. It is at this stage that we need the intervention of

the NGOs; they should incorporate this as part of their routine programmes, and assist us in making sure that we are able to carry through the programme.

Q: (Dr. Francis): Will this programme also be affected by the rigid timings when the clinics will be available and the personnel will be available. When we are thinking in terms of women, health education, and visual inspection, etc., the timings become very important. Is there any thought of changing the timings to suit the people and not to suit the staff?

A: (Dr. Ramachandran): As of today, it's just not possible.

(d) Co-ordinating the activities of community groups

Q: (Dr. Sen): Dr. Francis' presentation, and, in fact, almost every presentation of any NGO has diagnosed a problem, as well as suggested what needs to get done; what has been tried; which is very holistic, and which not only approaches health in a holistic manner, but sort of approaches the broader set of problems.

Now the business of the SHE clubs and these neighbourhood groups . . . it seems to me that every department now is thinking of setting up these groups. They've somehow discovered that getting women into a group seems to - well, either it's the fashion or it does the trick, whatever it is. But the point is that there are only so many groups that women can be a part of. It is very difficult to see how this goes forward. I am wondering, if the sources of ill health in the area includes such things as unsafe water, absence of sanitation and so on, whether it isn't possible in Bangalore City Corporation (if there is somebody there who actually has a concern and interest in these issues) to seriously try to make a break with this extremely vertical compartmentalised approach. This means that even in a programme of this type we have to be thinking about how you bring in at least the provision of safe water and improvement in sanitary facilities or even one of them along with the programme, and figuring out seriously how in fact the coordination is possible.

A: (Dr. Ramachandran): As far as this sort of a linkage is concerned, with UBSP it has been successful. We have 17 slums in Bangalore, which are under the UBSP project. Here, we have neighbourhood groups, which form the mini plan, that is, for the next year; they decide what they want. In these 17 slums, community toilets have been constructed with contribution in cash from the community. In fact, in some of the slums, nearly 25-30% of the money has been contributed by the people who are the beneficiaries of the construction of community latrines, mini water supply, borewells. So neighbourhood groups are working towards sanitation and various other programmes. But this is restricted to only about 17 slums of which I think only 11 slums are successful. In the remaining area, they have got into some trouble with the local elected persons. The SHE clubs are mainly concentrating on health programmes.

Comment (Dr. Ganapathy): I usually find myself on the other side of this question, complaining about rural services being neglected and the vast preponderance of services going to the cities.

But both these very thought provoking presentations have reminded me that even in India's urban areas, we have vast numbers of under-privileged people. I believe it's Ravi Duggal who has just collected some figures from the NFHS which shows that even of those availing of public health services, the people in the lowest ten per cent of the socio-economic strata get the least of the services; so I think we have a lot of ironing out to do even within the cities. Pat Biddinger asked this question about why we are all working 50 kms outside major urban areas. I think part of the answer is that even within the urban areas, we have not managed to do a good job; so you take it step by step.

12.2.2 Discussion outcome

- Positive developments in India include awakening of dalits, tribals and backward classes and mplementation of Panchayati Raj system.
- Positive developments with regard to Indian women include increased education of women and greater focus on ecological, gender and children's issues
- On paper there are plenty of health facilities, but utilisation is poor because of limited availability, accessibility and affordability.
- There has to be a change in the allocation of resources. The demand for such a change can be created only if INFORMATION is available.
- Information on the population's health status and health care infrastructure is needed.
- The Alapuzha study attempted to organise neighbourhood groups in order to create awareness about the urban basic services for the poor (UBSP). The study proved that women learn
  - the importance of self reliance
  - to stand together in difficulty
  - to analyse the socio-economic milieu
  - to identify and prioritize problems and find their own solutions
- About 19% of the Bangalore City population live in slums. It is critical to address the health needs of this population. This is the aim of the BCC programme. Surveys have shown that nearly 50% of people living in Bangalore slums avail of the services of private practitioners. It is hoped that they can be involved in the programme. The BCC has cooperated with NGOs in the past and such cooperation is imminent in this project as well.
- KMIO and BCC need to collaborate in the effort to control cervical cancer. A series of awareness programmes have to be instituted before the JHVs can start doing

(Contd.)

gynaecological examinations to detect cancer cervix. Ideally, this component should become a part of their routine activities. NGO collaborations are required to conduct awareness programmes.

- Even in a programme of this type, issues such as provision of safe water and improvement in sanitation must be addressed. The neighbourhood groups are doing so.

- The following plan could be followed: The BCC JHVs will identify women in the age group between 35 and 64 years of age with a potential cervical abnormality or with cancer cervix either symptomatically or through a physical examination. The JHV will refer women to a maternity home, which is the first referral unit. A gynaecologist at the maternity home will provide treatment or refer the woman to KMIO if necessary. All cases that are examined by the JHV will be recorded and a copy of this record will be sent to KMIO for monitoring. The project personnel will randomly check cases. The JHVs will carry sterile gloves and autoclaved specula in their kits. During the training programme they should be made aware of the importance of proper sterilisation of the speculum.

13. INTEGRATION OF CANCER CONTROL EFFORTS OF THE GOVERNMENT HEALTH INFRASTRUCTURE, NON-GOVERNMENTAL ORGANISATION AND PANCHAYATHI RAJ

13.1 Description of perspectives

13.1.1 The NGO perspective

(a) What can NGOs do?

- Provide health education: NGO representatives felt that they could enhance women's knowledge of reproductive health and illness (including cervical cancer); promote illness prevention; and increase men's awareness of reproductive health issues.
- Disseminate information on cervical cancer control to other NGOs.
- Motivate women to seek health services when required.
- Identify and facilitate the use of medical services for screening for cervical cancer.
- Detect cervical cancer (if health workers are part of NGO staff) and refer to appropriate medical institutions.
- Provide feedback on and be accountable for cervical cancer detection initiatives.
- Identify other systems of medicine to tackle women's health problems.

(b) What do NGO's expect from the government?

- Use the existing health infrastructure for awareness raising and cervical cancer screening.
- Provide training to NGOs (particularly, their health workers) in methods for the early detection of cervical cancer.
- Provide at least one lady medical officer in all primary health centres.
- Ensure medical facilities in all districts for the treatment of women with cervical cancer.
- Include cervical cancer prevention and control as one of the Ministry of Women and Child Development's priorities by allocating specific funds (including staff) for the programme.
- Promote awareness of cervical cancer through mass media (e.g. short documentaries, advertisements); involve members of gram panchayats, PHCs, anganwadis etc. in publicity campaigns.
- Set up a travel allowance for women diagnosed with cervical cancer who lack the resources to seek treatment at referral hospitals.
- Provide free treatment for poor patients.
- Narrow the communication gap between all levels of the government health system and NGOs.
- Provide the minimum financial inputs to meet cancer-specific activities such as publication of education materials.

(c) What do NGOs expect from KMIO?

- Provide NGO personnel with information on cervical cancer (for education purposes) and train them in the detection of cervical cancer (particularly health workers in NGOs).
- Provide health education and health worker training materials.
- Provide financial assistance for the administration of cervical cancer control programmes.
- Monitor and evaluate cancer control efforts.
- Ensure that the women who are referred to KMIO for a problem are given treatment in accordance with their financial status.
- Ensure that other cancer institutes will provide treatment to women diagnosed with cervical cancer.
- Organize workshops to facilitate sharing of experiences, to disseminate information, and to network with NGOs, government personnel and other cancer institutes.

13.1.2 The Government perspective

Dr. Nagaraj (Additional Director of Health Services) asserted the government health infrastructure's commitment to promoting women's health, and assured participants that the existing infrastructure would take part in a cervical cancer control initiative. The government's potential role was charted out as follows:

- Provide a structure for training grassroots-level government health workers and NGOs: Dr. Nagaraj suggested that a system for training could be developed through government medical colleges and district hospitals. Doctors, particularly gynaecologists, in these hospitals could be trained in cervical cancer detection and could, in turn, train JHVs and NGO staff at the district level. Thus, KMIO would not be overburdened with responsibility for training health workers.

There was some debate about the feasibility of this approach. Dr. Vallikad felt that training would have to include a component that involved examining women with and without cervical cancer. This aspect of the training was critical as the health personnel had to be able to identify the normal, abnormal and suspicious of malignancy status of the cervix. Unless this was done, the health personnel would make errors which itself would bring discredit to such a programme; this aspect of the training may not be possible at the district hospitals. Since KMIO was the only cancer centre in the State, it would have to be the site for training until peripheral cancer units were set up, she argued. Only quality training can contribute to the success of such a programme. Dr. Nagaraj expressed reservations about the feasibility of this plan in the context of a statewide initiative.

- Identify women medical officers or women medical practitioners at the taluk level for screening: Dr. Nagaraj stated that ensuring the presence of an LMO at every PHC is not likely to be feasible. An alternative that has been explored by the government in other projects has been the identification of women doctors at the taluk level who will be available to screen women for cervical cancer on a weekly or fortnightly basis. Dr. Vallikad felt that with appropriate training, lady health visitors (LHVs) could play the LMOs' role at the PHC. This has in fact been the case in several PHCs under the pilot project.

- Provide cobalt therapy units in 100 bed hospitals: The peripheral cancer units are being set up; currently, there is one in Mandya and Gulbarga districts. As part of a five-year project partially funded by the World Bank, cobalt therapy units have been envisioned for all 250-bed hospitals in the State. Since all district-level hospitals have at least 250 beds, radiotherapy facilities should be available at the district level. The project document has been submitted to the World Bank and awaits a staff appraisal.

Dr. Stjernsward noted *that it would be unethical to diagnose women with cancer without ensuring the availability of adequate treatment and palliative facilities.* He stressed that a

large proportion of women diagnosed with cancer during the initial stage of a cancer detection initiative are likely to have advanced disease; in this case palliative care would be an essential component.

- Involve other health-oriented projects in the State to promote awareness of cervical cancer: Dr. Nagaraj suggested that the information, education, communication (IEC) components of the World Bank funded India Population Projects may prove useful in terms of promoting cancer awareness. In addition, elected members of panchayats and Mahila Swasthya Sanghs may also play a role. Mr. Suresh noted that between 2,000 and 2,500 Sanghs were functioning in the State.

- Provide funds for poor women to avail cancer treatment: A fund of Rs.100 crores to assist poor individuals who are unable to meet medical expenditures may be set up by the Chief Minister. Travel allowances may also be available from this fund. Dr. Sen pointed out that some kind of concrete support in terms of transportation was required for women who are identified during screening by visual inspection as likely to have a cervical malignancy. She noted that the situation is similar to that of obstetric complications in which mortality cannot be reduced unless women with complications receive emergency medical attention. She suggested that it may be possible to provide transportation facilities for this select group of women through an existing health and development project such as those funded by the World Bank. Mr. Ghosal noted that government commitment on this issue would be forthcoming only after a detailed cost assessment was provided.

- Ensure free cancer treatment for poor women: Mr. Ghosal noted that the government could ensure free cancer treatment. However, identification of "poor" individuals was straightforward, according to Dr. Nagaraj. Dr. Vallikad noted that a social worker at KMIO identified patients for whom service fees could be waived. Dr. Hema Sridhar observed that even food is free for poor patients at KMIO.

- Prevent corruption in health institutions. There was considerable discussion about the prevalence of corruption in government health institutions. Noted one participant:

  When you go to the hospital, if at every level you have to pay somebody to register your case, to do this, to do that, you cannot call it free treatment. So then to talk about free - it will also be extended to cancer patients, I think it is a little bit absurd without addressing this issue.

- Provide funding for cancer-specific activities: a few NGO participants raised the question of government incentives to health workers for carrying out cervical cancer control activities. Dr. Vallikad *was strongly opposed to incentives since they were likely to lead to falsification of data on cancer control activities.* Dr. Sen pointed out *that incentives had wreaked havoc in the family welfare programme. This business of providing incentives leads to tremendous distortions in the way that service provision actually takes place. In*

this area [cancer control], where you are going to put in such a heavy component of awareness building, you should not be fooling around with this incentive business. The only reason it should be done is because women are suffering and dying and I think the community should be made aware of that.

- Provide funding for a cervical cancer control initiative spearheaded by KMIO: In response to a suggestion that concrete plans for launching a State-wide cervical cancer control initiative be made in terms of government support, Mr. Ghosal stated that an independent project would not be funded by the Government. However, the issue could easily be addressed within the larger health project that would be funded by the World Bank.

13.1.3 The KMIO perspective

- Provide training for village level workers: Training in cervical cancer detection could be provided by KMIO. However, KMIO would require outside funding to meet training expenses (such as travel allowances, publishing training materials). Thus far, expenses have been met from project funds that have run out. NGOs would have to bear the expenses for their staff who attend training sessions at KMIO. In addition, a small project team at KMIO has conducted the training; funding to continue hiring them would be required. In addition, the team would have to be strengthened if training on a larger scale is undertaken. Mr. Ghosal indicated that the Government would be likely to fund staff for training purposes.

Dr. Stjernsward suggested that there should be careful consideration of the approach to training. What should the duration of training be? What should be the content? How should it be assessed? What sort of follow-up evaluation should be conducted? Should there be a refresher course? All these questions must be dealt with in advance, he noted.

He also proposed a broader framework for the initiative: the joining of forces to control cervical cancer as well as sexually transmitted diseases such as HIV/AIDS. Due to the inter-relatedness of the issues involved in preventing this range of diseases, it would make most sense to address them jointly in a training programme. Dr. Vallikad pointed out that the KMIO-BCC project is addressing this particular issue.

Dr. Sen stated that the development of training and health education materials should involve individuals who have an expertise in audio visual communication, mass media and so on, so that information is "technically accurate and user-friendly."

- Monitor and evaluate activities: KMIO would continue to monitor and evaluate cervical cancer control activities (so long as funds to support field staff is available). Dr. Dara Amar, St. John's Medical College suggested that medical colleges in Bangalore (and in other parts of the State) could also be involved in carrying out this component.

13.1.4 The Community-Medicine perspective

Dr. Dara Amar, St. John's Medical College, outlined an approach to cervical cancer control from a community medicine perspective. He began by addressing the issue of training grass-roots level workers in cancer control. He stated that medical colleges can play a vital role in training and community outreach since a large number of resource people (faculty and students) who can be involved in the training programme were available.

He suggested that a team comprising of individuals from community medicine, gynaecologic oncology and clinical pathology should conduct the training. Village-level health workers and doctors should visit the cancer hospital, and gain experience in conducting gynaecological examinations. They should see women with normal and abnormal cervices. Training should also address issues such as how to organise women and participatory methods in awareness creation such as body mapping, focus group discussions etc. Training should include a discussion about what cancer cervix is and what it is not. What happens when a woman is diagnosed with cancer? What is the mechanism of referral (including names and addresses of resource persons and institutions)? What are the financial and time commitments on the part of the patient? Action plans for all those who are diagnosed with cancer cervix should be made explicit during training. He stressed the need for refresher programmes during which field workers could solve problems encountered during the implementation of the programme.

Dr. Dara felt that evaluation of the training programme is essential. The crucial aspect to be evaluated is the training process:

> *I would be much more interested in the process of training. How long did they come to this training? Were they consistent? Were they paying attention? Did they ask questions? What types of questions were asked? What responses did you get for your clarification?*

Dr. Dara suggested that one way of analysing training sessions is by recording them on video; trainers could then analyse the programme.

The keys to implementing a cervical cancer control programme are women. Local women's groups should be involved in the process of implementation since this "ensures [their] ownership of the entire programme," noted Dr. Dara.

Equally important in the success of the programme is ensuring that treatment facilities of high quality exist and are accessible. Treatment should be ensured for women referred through the community-based cervical cancer control project since they are "important ambassadors for motivating other women from their villages [to seek medical services]." It is crucial that treatment facilities are established before embarking on an effort to downstage cervical cancer because:

> *When you raise the expectation limit and create a demand, you better fulfil that demand; if you don't, the negative feedback is so bad that it would have been better to leave them alone.*

Thus, cobalt therapy units must be available at the district level. A clear referral system must be put in place, and made known to all individuals involved.

Lastly, medical colleges can be involved in the implementation part of a cancer control initiative as well. They can help develop audio-visual aids for field use; monitor and evaluate the referral system; and be involved in counseling women diagnosed with cancer.

13.2 Discussion outcome

- Dr. Vallikad felt that training would have to include a component, which involved examining women with, and without cervical cancer; this may not be possible at district hospitals. Since KMIO is the only cancer centre in the State, it would have to be the site for training until peripheral cancer units were set up, she argued. Dr. Nagaraj expressed reservations about the feasibility of this plan in the context of a Statewide initiative. Equally important in the success of the programme is ensuring that treatment facilities of high quality exist and are accessible.

- Dr. Nagaraj stated that ensuring the presence of an LMO at every PHC is not likely to be feasible. An alternative that has been explored by the government in other projects has been the identification of women doctors at the taluk level who will be available to screen women for cervical cancer on a weekly or fortnightly basis. Dr. Vallikad felt that with appropriate training, lady health visitors (LHVs) could play the LMOs' role at the PHC. This has been the case in several PHCs under the pilot project.

- Since all district-level hospitals have at least 250 beds, radiotherapy facilities should be available at the district level. Since a large proportion of women diagnosed with cancer during the initial stage of a cancer detection initiative are likely to have advanced disease; a palliative care would be an essential component.

- Dr. Nagaraj suggested that the information, education, communication (IEC) components of the World Bank funded India Population Projects may prove useful in terms of promoting cancer awareness. In addition, elected members of panchayats and Mahila Swasthya Sanghs may also play a role.

- Mr. Suresh noted that between 2,000 and 2,500 Sanghs were functioning in the State. A fund of Rs.100 crores to assist poor individuals who are unable to meet medical expenditures is set up by the Chief Minister. Travel allowances may also be made available from this fund. Mr. Ghosal noted that the government could ensure free cancer treatment.

- The prevalence of corruption in government health institutions should be addressed as an issue when talking about the free treatment in these institutions.

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- On the issue of providing funding health workers for cancer-specific activities, Dr. Vallikad strongly opposed to incentives since they were likely to lead to falsification of data on cancer control activities. Dr. Sen pointed out that incentives had wreaked havoc in the family welfare programme. If collaboration were to succeed it would have to be based on trust and commitment. Raising community awareness was "part and parcel" of NGO activities and "does not cost anybody anything" as long as the technical information was available. However, KMIO would require outside funding to meet training expenses (such as travel allowances, publishing training materials). NGOs would have to bear the expenses for their staff who attend training sessions at KMIO. Mr. Ghosal indicated that the Government would be likely to fund Govt. staff for training purposes.
- Framework for joining of forces to control cervical cancer as well as sexually transmitted diseases such as HIV/AIDS was proposed. Due to the inter-relatedness of the issues involved in preventing this range of diseases, it would make most sense to address them jointly in a training programme.as already addressed by the KMIO-BCC project.
- Development of training and health education materials should involve individuals who have an expertise in audio visual communication, mass media and so on, so that information is "technically accurate and user-friendly."
- KMIO would continue to monitor and evaluate cervical cancer control activities (so long as funds to support field staff is available) along with other medical colleges of Bangalore if feasible. Medical colleges can play a vital role in training and community outreach since a large number of resource people (faculty and students) who can be involved in the training programme were available.
- Training should include identification of normal and abnormal cervices, how to organise women and participatory methods in awareness creation such as body mapping, focus group discussions etc. Training should include a discussion of what cancer cervix is and what it is not. What happens when a woman is diagnosed with cancer? What the mechanism of referral is (including names and addresses of resource persons and institutions). What the financial and time commitments on the part of the patient are. Action plans for all those who are diagnosed with cancer should be made explicit during training. There is a need for refresher programmes during which field workers could solve problems encountered during the implementation of the programme. One way of analysing training sessions was by recording them on video; trainers could then analyse the programme.
- A clear referral system must be put in place, and made known to all individuals involved.

14 CONCLUDING SESSION

The concluding session of the workshop was devoted to an elaboration of the nature of NGO involvement in downstaging cervical cancer. A number of NGO participants had felt that government representatives at the workshop had addressed the collaboration in narrow financial terms, rather than in the more broad terms of felt needs of those involved. A space was created, therefore, during the last session for NGO representatives to voice their concerns, and to set their terms for collaboration.

There was some debate over the relationship between NGOs and the government and KMIO. One participant felt that government representatives at the workshop had responded with unwarranted suspicion when NGOs pointed out that a certain amount of financial resources would be required to carry out their role in the initiative to downstage cervical cancer. It was felt that if a collaboration was to succeed it would have to be based on trust and commitment; commitment in emotional and financial terms on the part of the government. However, another participant argued that raising community awareness was "part and parcel" of NGO activities and "does not cost anybody anything" as long as the technical information was available.

At this juncture, the group concluded that further discussion of the terms of the collaboration could be postponed until NGOs had time to discuss the project with other members of their organisation. A follow-up meeting would be scheduled to chart out the specifics of the initiative.

15 SUMMARY

The workshop in its several sessions clearly brought out the need for a concerted drive on the field to implement community approaches in the early detection of cancer cervix. Shri S.V. Ghosal, Additional Chief Secretary, Government of Karnataka, referred in his welcome address to the "frightening dimensions of cervical cancer and the awful inadequacies of the present approach, in the coverage of the screening" etc. He also pointed out that " the battle front is not there in the hospitals but in the districts, in the families". Many participants underscored the need for intense collaborations between government health services, medical institutions, NGOs and other local bodies. The empowerment of women will need multiple strategies and multiple alliances to develop a total health package for women.

APPENDICES

APPENDIX 1

REPORT OF POST WORK SHOP ACTIVITIES UNDERTAKEN BY THE DEPARTMENT OF GYNAECOLOGIC ONCOLOGY

Period 1 January 1996 – 30 September 1998

1.0 DOWNSTAGING CARCINOMA CERVIX IN THE INDIAN CONTEXT - PHASE III - EARLY DETECTION OF CERVICAL CANCER IN THE URBAN UNDER-PRIVILEGED WOMEN

Aim: To develop a strategy for early detection of cervical cancer in the urban under-privileged women using the existing government health infrastructure

These efforts consisted of two activities –

- Knowledge, Attitude and Practice survey on cancer cervix in the urban underprivileged women to assess the level of awareness in a representative sample of these women.
- Collaboration with the Bangalore City Corporation (BCC) for early detection of cancer cervix in the urban underprivileged women in Bangalore

1.1 Knowledge, attitude and practice survey

The questionnaire used for the knowledge, attitude, and practice (KAP) survey on cervical cancer was the same that had been used for the survey that had been undertaken in Phase I of the study. The same staff who had undertaken the previous survey in Phase I undertook this survey and hence the interviewer variation has been minimised. The survey commenced on 12 March 1996 and was completed on 31 January 1998. During this time period, the staff were also simultaneouly involved in other activities i.e. training of the NGO staff, training of the BCC staff, passive monitoring of the collaboration with the BCC. They were also involved in running the Dysplasia Clinic at the Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology.

At present 464 slums have been identified within the limits of the Bangalore City Corporation. The stratified random sampling method was used to select 52 slums. The total female population in the Bangalore slums is estimated to be more than 4,00,000. The number of women who would be aged between 20 and 60 years would be 20% of these populaiton, i.e. about 81500. The aim was to cover about 11% of these target population, i.e. 8965. The total number of respondents who finally participated in the KAP Survey is 4275. None of the women refused to answer the questions posed by the project staff.

The salient observations have been classified into the following tables

1. A brief profile of the sample
2. Awareness about cancer

3. Awareness about cancer cervix
4. Awareness about a test for early detection of cancer cervix

1. A brief profile of the sample

Table 1: Age distribution of the interviewed women

Age in years	*Number*	*%*
< 30	595	13.92
30 – 39	1356	31.73
40 – 49	1346	31.48
50 – 60	920	21.52
> 60	58	1.35
Total	4275	100.00

Table 2: Religion of the interviewed women

Religion	*Number*	*%*
Hindu	3236	75.7
Muslim	775	18.1
Christian	252	5.9
Others	12	0.3
Total	4275	100.00

Table 3: Educational status of the interviewed women

Education	*Number*	*%*
Illiterate	3176	74.29
Primary (1-4)	444	10.38
Secondary (5-7)	596	13.94
High (8-10)	54	1.28
PUC +	5	0.11
Total	4275	100.00

Table 4: Age at Marriage reported by the inteviewed women		
Age in years	*Number*	*%*
< 15	2877	67.29
16 – 20	1251	29.26
21 – 25	117	2.75
> 26	30	0.70
Total	4275	100.00

2. Awareness about cancer

These consist of responses to questions on awareness about cancer.

Table 5: Awareness about a disease called cancer		
Response	*Number*	*%*
Yes	834	19.51
No	3441	80.49
Total	4275	100.00

Table 5.1: Can cancer be treated?		
Response	*Number*	*%*
Yes	271	6.33
No	187	4.37
Sometimes	22	0.53
Don't Know	354	8.28
Unaware	3441	80.49
Total	4275	100.00

Table 5.2: Can cancer be cured?		
Response	*Number*	*%*
Yes	265	6.19
No	194	4.53
Sometimes	23	0.56
Don't Know	352	8.23
Unaware	3441	80.49
Total	4275	100.00

Table 5.3: Is cancer dangerous?		
Response	*Number*	*%*
Yes	823	19.25
No	11	0.26
Unaware	3441	80.49
Total	4275	100.00

3. Awareness about cancer cervis

These consist of responses to questions on awreness about cancer

Table 6: Awareness about cancer cervix		
Response	*Number*	*%*
Yes	398	9.30
No	5	0.11
Don't Know	431	10.08
Unaware	3441	80.49
Total	4275	100.00

Table 6.1: Awareness about the symptoms of cancer cervix		
Symptoms	*Number*	*%*
White Discharge	34	0.79
Heavy Bleeding	16	0.37
Pain	7	0.18
Don't Know	772	18.06
Unaware	3441	80.60
Total	4275	100.00

Table 6.2: Can cancer cervix be treated?		
Response	*Number*	*%*
Yes	198	4.65
No	51	1.19
Sometimes	8	0.17
Don't know	572	13.39
Unaware	3441	80.60
Total	4275	100.00

Table 6.3: Can cancer cervix be cured?		
Response	*Number*	*%*
Yes	196	4.58
No	51	1.19
Sometimes	8	0.17
Don't know	574	13.46
Unaware	3441	80.60
Total	4275	100.00

Table 6.4: Is vaginal discharge normal?		
Response	*Number*	*%*
Yes	5	0.11
No	3305	77.32
Don't know	965	22.57
Total	4275	100.00

Table 6.5: Is inter-menstrual bleeding normal?		
Response	*Number*	*%*
Yes	5	0.11
No	3299	77.16
Don't know	971	22.73
Total	4275	100.00

Table 6.6: Is post-menopausal bleeding normal?		
Response	*Number*	*%*
Yes	4	0.09
No	3299	77.16
Don't know	972	22.75
Total	4275	100.00

4. Awareness about a test for early detection of cancer cervix

These consist of responses to questions on awareness about a test for early detection of cancer cervix

Table 7: Have you heard of a test for Cancer Cervix?		
Response	*Number*	*%*
Yes	8	0.17
No	4245	99.29
Not sure	22	0.54
Total	4275	100.00

Table 7.1: Have you had the test?		
Response	*Number*	*%*
Yes	6	0.15
No	4197	98.17
Not sure	72	1.68
Total	4275	100.00

Table 7.2: Are you interested in undergoing the test?		
Response	*Number*	*%*
Yes	3014	70.50
No	1250	29.23
Not sure	11	0.27
Total	4275	100.00

Table 7.3: Do you need husband's/elder's/children's consent for the test?		
Response	*Number*	*%*
Yes	1619	37.87
No	2387	55.84
Not sure	269	6.29
Total	4275	100.00

This information will have to be correlated with the survery that has been conducted earlier in rural areas around Bangalore.

1.2 Collaboration with the Bangalore City Corporation (BCC)

The strategy implemented was similar to that attempted in Phases I and II as was discussed at the workshop. The activities consisted of training the BCC staff and passive monitoring by the KMIO team.

Training programme

The training of the JHVs, LHVs, JHVs, and Medical Officers of the Bangalore City Corporation for early detection of cancer cervix in urban underprivileged women commenced on 6 February 1996. This training programme consisted of the original training schedule to which components on prevention of AIDS and STDs were added. The staff of the Department of Microbiology, Kidwai Memorial Institute of Oncology, undertook these aspects.

The details of the training are given below:

There were 79 Medical officers and 319 Health Visitors trained at KMIO. The staff were deputed for training and their travel and daily allowance for the period of the training was paid by the BCC. The BCC also made available the specula, stationary, torch and gloves that comprised of the kit. The health education material and training manual was provided by the project of the Department of Gynaecologic Oncology.

Passive monitoring by KMIO project staff

The KMIO project staff have attended 23 monthly meetings at the BCC and collected the referral slips of all those women who received health education or had been examined. A list of the women who reached KMIO after being referred by the BCC personnel was given to the BCC during the meeting. Difficulties faced by the BCC staff on the field were discussed at this

meeting. Unlike in the other two phases the KMIO project staff did not re-examine a sample of the women who had been examined in order to monitor the accuracy of the examination nor were attempts made to track noncompliant women and ascertain their reasons for noncompliance for the test and for referral - thus the monitoring was passive and basically consisted of motivating BCC health worker once a month.

Summary of the Activities under taken - 1 January 1996 - 31 December 1997

1. The number of staff trained

Junior Health Visitor	-	319
Medical Officers	-	79

2. Number of monthly meetings attended

@4 days per month	-	96

3. Women contacted for health education by JHV	-	3978
4. Women underwent Visual Examination	-	3976
5. Number of women who refused	-	2

6. Classification of the cervix by visual examination

Normal	-	2667
Abnormal	-	1295
Suspicious of Malignancy	-	14

7. Number of women who reached KMIO (including those not referred)	-	294

Diagnosis		
Normal	-	265
Pre malignant lesions	-	2
Cancer cervix stage IIB	-	1
Cancer cervix stage IIIB	-	9
Cancer Ovary	-	2
Cancer Endometrium	-	2
Benign Tumor (Fibroid uterus)	-	13

1.3 Summary and Conclusions of Phase III

- The urban under-privileged women
  - are generally illiterate
  - are married before the age of 15 years
  - < 20% have heard about cancer
  - <10% have heard about cancer cervix
  - <1% are aware about the symptoms of cancer cervix
  - <1% are aware that a test is available for early detection of cancer cervix
  - >70% are interested in undergoing the test
- This group of women needs intervention
- Intervention by the existing health infrastructure is possible
- The Bangalore City Corporation health personnel have shown co-operation and motivation for this intervention. As we go to print, the Bangalore City Corporation has requested us to continue training medical officers and paramedical staff. This will commence in July 1998 and will be continued during the report writing phase. This demand on their part is highly gratifying and encouraging.
- The coverage so far has indicated that:
  - 9.1% had a gynaecological problem
  - 4.8% had a gynaecological malignancy
  - 4.4% had a benign gynaecological problem
  - 3.4% had cancer cervix
  - 0.68% had premalignant leisions of the cervix
- The coverage perhaps could be increased by involving the urban NGOs

In the initial phase of the intervention more number of advanced leisons will be detected and it is only as the intervention progresses that the early and preinvasive cases will be detected

2.0 POST WORKSHOP COLLABORATION WITH NGOS

2.1 Follow-up meeting with NGOs

A follow-up meeting to plan the implementation of a community approach to downstage cancer cervix was held on 29 February 1996 at the PRAXIS Training Centre, at Doddaballapur. NGOs from Kolar, Tumkur, Bangalore, Bellary, Mandya district and (organisations from Andhra Pradesh) were present. At the meeting, the following issues were discussed:

- Components of the health education and training programme for early detection of cancer cervix;
- NGOs were asked to send relevant information such as the number of PHCs in their area, the list of villages covered by each PHC, total population, distance from each village to the PHC, the names of the PHC staff, etc., in order to facilitate project planning by the Department of Gynaecologic Oncology, KMIO;
- NGOs were assured that their health staff (i.e. trained ANM/Nurse/Doctor) could be trained by the Department of Gynaecologic Oncology, KMIO;
- KMIO project staff provided details of the kit that is necessary to conduct gynaecological examinations, the record keeping forms, and the referral system.
- Some NGOs requested that training sessions be conducted for their staff so that they could implement the health education aspect of the early detection of cancer cervix activity in their areas.
- NGO's from other states were requested to provide financial support for travel besides of course local hospitality to the project team of the Department of Gynaecologic Oncology, KMIO.

2.2 Training sessions held for NGOs

The following NGOs requested us to conduct one day training sessions:

Place	Organiser (NGOs who participated)	Date
Bangalore	Joint Women's Programme	29 January 1996
Bangalore	Mahila Samakhya (Fedina, Praxis, PMSR, Vidyaniketan, Ashraya, Vikasana, Birds, Sandur Mines, Rural community health and development, Mahila samakhya from Raichur, Gulbarga, Bijapur, Mysore, Bidar, Bangalore.)	6 April 1996

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Place	Organiser (NGOs who participated)	Date
Tumkur	REDS (WLARS, AKAY, IDS)	12 April 1996
Mulbagal	Prakruthi (Sunanda, Walkwide, Janachetana, RSC)	10 May 1996
Kollegal	PMSR	4 June 1996
Bangalore	Fedina	7 June 1996
Penukonda	Young India Project	19 July 1996
Bangalore	Samaja Vikasa Kendra	17 August 1996
Ramanagaram	Sakti	27 September 1996
Bangalore	Samaja Vikasa Kendra	7 November 1996
Bangalore	Sakti	4 December 1996
Sri Kalahasti	Young India Project	12 January 1997
Penukonda	Young India Proejct	7 August 1997

3.0 FUTURE PLANS – PHASE IV

This will consist of integrating the concepts discussed in Section IV and the experiences of Phases I-III in a field intervention.

Eighteen NGOs have expressed a desire to collaborate with KMIO to promote early detection of cancer cervix. They have sent details of the PHCs in the areas in which they function. There are 186 PHCs in these areas. The Department of Gynaecologic Oncology, KMIO will train the health personnel in these PHCs (on early detection of cancer cervix). This would entail working in about 12 districts in Karnataka.

The NGOs have been requested for information about local private institutions/hospitals or local gynaecologists who would be interested in being involved in the project; this would ensure that additional referral services are available in all project areas

As discussed during the workshop, the plan is to involve women panchayat members to impart health education and ensure that PHCs provide cervical cancer screening services to women.

A proposal is in preparation in order to apply for the necessary financial support that will be required to undertake this phase.

APPENDIX 2

WORKSHOP PROGRAMME

27 November 1995

8.00 am	Registration	
9.00 am	Inauguration	
	* KMIO initiatives & Welcome	: Dr. Elizabeth Vallikad
	* Opening Remarks	: Dr. J. Stjernsward
	* Inaugural Address	: Shri S.K. Ghosal IAS
	* Chief guest	: Shri R. Suresh IAS
	* Presidential Address	: Dr. N. Anantha
	* Vote of Thanks	: Dr. Hema Sridhar
10.00 am	Tea Break	
10.15 am	Cancer Cervix – A Preventable Disease Prof. Margaret Davy	
10.45 am	Organised Screening Programme for Cancer Cervix: Lessons applicable to developing countries Prof. Matti Hakama	
11.15 am	Discussion Moderator – Prof . N. Anantha	
11.30 am	Strategies for the control of cancer cervix in developed and developing countries Prof. Jan Stjernsward	
12.00 noon	The National Cancer Control Programme and the problem of cancer cervix Dr. K. Dinshaw	
12.30 pm	Discussion Moderator – Prof. Hema Sridhar	
12.45 pm	The problems of Cancer Cervix in India Community awareness and attitude Experiences of the KMIO study Prof. Elizabeth Vallikad Moderator - Prof. Dara Amar	

1.15 pm	Discussion
1.30 pm	Lunch Break
	Experiences of the KMIO study continued
2.00 pm	Technical Feasibility Ms. Binu Kuruvilla
2.20 pm	Problems of the women
	Ms. Kalpana
2.30 pm	Problems of the Health Infrastructure
	Dr. K. Umadevi
2.40 pm	Discussion
	Moderator – Prof. Gita Sen
3.45 pm	Tea Break
	The Health Infrastructure – Potentials and Limitations
4.00 pm	Dr. Srinivasa Gowda
4.10 pm	Dr. Rukmini Ramachandra
4.20 pm	Ms. T. Nirmala
4.30 pm	Ms. Anthony Mary
4.40 pm	Ms. Uma
4.50 pm	Discussion Moderators – Ms.Srilatha Batliwala Dr. G.V. Nagaraj

28 November 1995

	The Non-Governmental Organisations – A catalytic Role in the ealry detection of cancer cervix The NGO perspective – KMIO Experience
9.00 am	Ram Esteeves – ADATS
9.15 am	Alex Tuscano – PRAXIS

9.30 am	The KMIO – NGO Experience Ms. Kalpana
	Lessons learned from a community based preventive Health programme – Implications for early detection of cancer cervix
9.45 am	Dr. Nergis Mistry
10.15 am	Ms. Srilatha Batliwala
10.45 am	Tea Break
11.00 am	Discussion Moderator – Dr. Shobha Raghuram
	Early Detection of Cancer Cervix : Health care and the Panchayat Raj
11.30 am	Role of Panchayat Raj Institutions in the Early Detection of cancer cervix Shri Satish Chandran
12.00 noon	Role of Women Panchayati Members in Creating People's Health Awareness Ms. Suman Kolhar
12.30 pm	Experiences with Panchayati Raj and the Government Education Infrastructure Ms. Nandana Reddy
1.00 pm	Discussion Moderator – Dr. Revathy Narayanan
1.30 pm	Lunch – Break Early Detection of Cancer Cervix – Health care in Underprivileged Urban women
2.00 pm	Scenario of Health Care facilities for women in Urban areas Prof. C.M. Francis
2.30 pm	Development of a strategy for early detection of Cancer Cervix in Underprivilaged Women of the Areas of Bangalore City Corporation Dr. Mala Ramachandran

3.00 pm The Problem of Reproductive Tract Infection
Prof. Elizabeth Vallikad

3.30 pm Discussion
Moderator – Dr. Saraswathy Ganapathy

4.00 pm Tea Break

29 November 1995

Planning the Future – Collaboration and Strategies

10.00 am The need for a wider campaign against cancer cervix

Prof. Elizabeth Vallikad

Responses from NGO's

Responses from Government of Karnataka

Shri M.P. Prakash
Shri K.P. Pandey IAS
Shri G.R. PremKumar IAS
Shri R. Suresh IAS
Smt. R.S. Sujata IAS
Dr. G.V. Nagaraj

Discussion
Moderators – Shri S.K. Ghosal IAS
Prof. Gita Sen

Lunch Break

2.00 pm Alternate strategies and policy choices for work in Karnataka

The Economics of Preventive Women's Health Activity in Early Detection of Cancer Cervix
Prof. Gita Sen

Preventive Women's Health Acticvity of NGO's in Early Detection of Cancer Cervix
Dr. Shobha Raghuram

A Preventive Health Activity o the Panchayat System In Early Detection of Cancer Cervix

Ms. Srilatha Batliwala

Persoectives in the Department of Community Medicine of a Medical College for Early Detection of Cancer Cervix

Prof. Dara Amar

Prof. Elizabeth Vallikad

Discussion

Moderator – Prof. Jan Stjernsward

APPENDIX 3

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Bangalore Urban District, Bangalore.

Cancer cervix is the most common cancer affecting Indian women. Most of the affected women are - aged between 35 and 64 years, come from rural India and seek treatment with advanced diseases. This being the case the outcome of the treatment is far from satisfactory.

These problems of cancer cervix as perceived at the Department of Gynaecologic Oncology, Kidwai Memorial Institute of Oncology, Bangalore, led to the experiment to assess the possibility of introducing Visual Inspection of the cervix to downstage (early detection of) the disease - a concept suggested by the WHO for use in developing countries because of the financial implications of introducing cytology screening. There is no doubt that the existing health infrastructure is the only network through which such a programme could be implemented. These endeavours were supported by the Indian Council of Medical Research and the WHO through the Ministry of Health, Government of India and the Department of Health and Family Welfare, Government of Karnataka.

The efforts were further supported by two NGO's - PRAXIS and ADATS in order to assess the role that they as NGOs could play to contribute towards the early detection of cancer cervix. The experience of these efforts suggested that in order to achieve any progress, the problem of prevention and early detection of cancer cervix must be taken out into the community. Thus the workshop was conceptualised and held on 27 - 29 November 1995 at the Institute for Social and Economic Change, Bangalore. The workshop and subsequent followup work was supported by Hivos (Humanist Institute for Cooperation with Developing Countries) India Regional Office and the MacArthur Foundation, USA.

The workshop attempted to bring together representatives of non-governmental organistations, the government and government health infrastructure, social activists, social scientists, academicians and health professionals. At every stage an attempt was made to provide the participants with a frame of reference to understand and assess the issues involved.

The experience of the workshop confirmed our impression that progress in the practical application of the principles of Preventive Oncology is entirely dependent on the interest, participation and commitment to a partnership of the community and health professionals (both government and nongovernment).

Thus though it would be overwhelmingly impractial in the Indian situation to have an organised cytology based screening programme for cancer cervix, which is scientifically superior to visual inspection, we cannot wait indefinitely for cytology to be made available. *The introduction of visual inspection should be seen as a financially viable method of inculcating health awareness about cancer cervix and, in the years to come, a harbinger of a cytology screening programme in India.*

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